Why don’t NHS healthcare professionals recommend patients use web-based decision support tools? Interviews from the front line.

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Why don't NHS healthcare professionals recommend patents use web-based decision support tools? Interviews from the front line.

Glyn Elwyn, Andrew Rix, Tom Holt, Deborah Jones

Cochrane Institute of Primary Care and Public Health
Neuadd Meirionydd
School of Medicine
Cardiff University
Heath Park
United Kingdom
CF14 4YS

Glyn Elwyn, professor, elwyng@cardiff.ac.uk
Andrew Rix, independent researcher, andrewrixhome@gmail.com
Tom Holt, independent researcher, tbholt1@gmail.com
Deborah Jones, independent researcher, deb.jns64@gmail.com

Address for correspondence: Glyn Elwyn - glynelwyn@gmail.com

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Summary

Focus

- Research studies demonstrate that engaging patients in the use of decision support (decision aids) is beneficial but take up is low
- Clinicians are in a position to advocate the use of decision support by but do not appear to do so.

Key messages

- Reluctance to point patients in the direction of decision support is based on a complex mixture of professional attitudes, difficulties in incorporating the tools into existing work patterns and competing organisational pressures, such as targets
- This reluctance will not be overcome simply by making more tools available and more accessible
- When appropriately directed, a significant number of patients do use the decision support and say they find them useful.

Strengths and Limitations

- The evaluation study upon which these results are based set out to explore patterns of usage but turned to examine why take up was lower than expected
- The evidence comes mainly from 57 qualitative interviews with healthcare professionals taking part in the introduction of six web-based decision support tools hosted on the NHS Direct website
- Low take-up reduced the opportunity to obtain evidence from patient users.

Abstract

Objective: To assess whether clinical teams would direct patients to use web-based patient decision support interventions (DESIs) and whether patients would use them.

Design: Mixed methods using concurrent and retrospective semi-structured interviews, web server log analysis and surveys.

Participants and settings: 57 professionals (nurses, doctors and others) in orthopaedic, antenatal, breast, urology clinics and in primary care practices and 10 patients across 22 NHS sites given access to DESIs hosted on the NHS Direct web-site.

Results: Fewer than expected patients were directed to use the web tools. Technical problems partly contributed but the low uptake was mainly explained by clinicians' limited understanding of how they should be located in clinical pathways, their perception that 'shared decision making' was already commonplace and that some patients are resistant to being involved in treatment decisions. External factors, such as efficiency targets and 'best practice' recommendations were cited as having a significant negative influence on clinicians' decisions to refer. Clinicians did not feel the need to direct patients to use decision support tools, web-based or not, and, as a result, felt no requirement to change existing routines. However, the data also showed that many patients, when directed to these tools, were willing to access and use them and found them helpful. Uptake is highest when clinicians set expectations that these tools are integral to practice and embed their use into clinical pathways.

Conclusions: Evidence of patient benefit from a Cochrane review and making DESIs freely available via the web are not sufficient drivers to guarantee routine use. Changes are needed in attitudes and skills as well as system support to reach organisation-wide agreement about the role of these interventions and their location in clinical pathways.

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Introduction

Are clinical teams willing to ask patients to use decision support interventions, when hosted on the web? A decade of research has demonstrated consistent positive outcomes when patient decision support interventions, often called decision aids, are evaluated in randomised controlled trials (1). Use of these interventions is advocated in order to help achieve shared decision making – where patients and clinicians work together to arrive at decisions that best match the informed patient preference (2). These interventions typically consider clinical situations where there are reasonable alternatives. Typical examples are whether to proceed to a total knee replacement or use alternative treatments or whether to accept or decline an amniocentesis, a procedure that runs the risk of leading to a miscarriage. When these interventions are used, patient knowledge increases, risk perceptions are more accurate, patients feel more actively involved in decisions and often tend to make more conservative choices, especially when considering discretionary surgery (1).

Despite good evidence and policy support, studies have revealed resistance to the implementation of shared decision making and decision support (3). Professionals often hold the view that they 'already do' shared decision making, that the interventions promoted lack applicability to individual patients and that there is insufficient time to involve patients in decisions (4). To date, only a few studies have addressed the use of implementing these interventions in routine clinical settings (5). Many obstacles have been described and it is too early to say whether the benefits observed in randomised trials can be replicated (Francis Légaré et al., 2010). As yet, there has been no large scale study to assess the uptake possible in pragmatic settings (7).

Responding to the potential benefits of shared decision making and the use of patient decision support, the NHS in England invested approximately £1.5M in 2009-10 creating a platform of web-based patient decision support, as part of an England-wide shared decision making programme. NHS Direct was commissioned by the East of England Strategic Health Authority to adapt, host and pilot the introduction of web-based decision support interventions into the NHS, as part of the Quality Innovation, Performance and Prevention Programme.

A multi-phase programme of work was proposed, with the aim of creating an easily accessed web-based set of patient decision support tools hosted on an NHS web-platform coupled with telephone support (2). An external evaluation was set up to assess whether clinical teams would direct patients to these tools and to assess uptake and use. This article reports the main findings of the evaluation, based on web-server logs and interviews with clinical staff.

Methods

Two phases were planned. In each phase, three web interventions were adapted and hosted on NHS Direct's website. NHS sites were recruited into evaluation pilots of approximately three-month's duration – see Table 1.

In phase 1, the three interventions were adaptations of programmes originally developed by the Foundation for Informed Decision Making, Boston (see Table 1). The prostate web interventions were originally produced in DVD versions and had been previously introduced into some clinics in England (8)(9).

Eight NHS clinics, across England, some with previous involvement in the development of the DVD and web-based versions, agreed to introduce patients to them. For the knee condition, patients referred to secondary care were identified by staff at the relevant clinics and directed to access the web-based tools to read information about a range of treatment options, e.g. physiotherapy, injections and knee replacement. If patients completed the use of the web tool, a personalised summary was generated that listed their preferred treatment. Patients were asked to either print this summary or, when they attended their next clinic appointment, to ask for the summary to be discussed with them. It had estimated that 360 patients across three clinics would be eligible to use the knee osteoarthritis web intervention during the evaluation period. Similar methods were applied to the web tools for BHP and LPC.

In phase 2, three interventions were adapted from tools developed at Cardiff University (see Table 1). Data was collected from 7 breast cancer and 7 antenatal outpatient clinics recruited by NHS Direct (Table 2). Estimates of patients potentially eligible for these tools had been set at 50 per site, a pool of around 700 patients. Primary Care Trusts in England were asked to contact primary care practices, alerting clinicians to the availability of the PSA decision support tool.

Data Collection

Data was collected in each phase for a maximum of 14 weeks using the following methods:

Referral data: In both phases, clinics kept a record of patients directed to use the tools. Patients were given unique access codes, enabling anonymised tracking of server web logs.

Web logs: web server log data was collected, tracking access (content and duration) of each web page viewed.

Interviews with health professionals: After informed consent was obtained, semi-structured interviews were conducted with medical and nursing specialists responsible for implementing the intervention at each clinic. The respondents were asked their views about the web-based patient decision support and the role they might play in their work. Interviews were conducted at the start, mid-point and end of the pilots, audio-recorded and transcribed. Results from the evaluation of the first phase led to a change of focus for the evaluation of the second phase.

Patient interviews and surveys: Short survey tools addressed questions about usability and assessed knowledge about the relevant condition. Patients also consented to a semi-structured telephone interview about their experience of using the site.

Data analysis: Web server log data were verified, cleaned and analysed by TH. AR and DJ coded the interviews independently, meeting to agree coding frames, prior to jointly categorising the data into themes related to clinician views about the decision support tools and their willingness to direct patients to them.

Results

Patient's access and use: Records indicate that 162 of the estimated potential pool of 360 patients were offered access to the OA knee tool: 102 of the 162 visited (63%) visited the site, at least briefly. A total of 38 (23%) provided some information; 27 patients (26%) used the site in sufficiently to produce a summary sheet that could be used in a future clinic appointment. This number represents 7% of those estimated to have been eligible. No estimates were available for eligible patients in relation to BPH and

LPC, or for numbers directed to the sites. Web log data showed 24 and 8 unique visitors to the LPC and BPH sites respectively, resulting in 5 and 2 patients using the sites from introductory pages to summary page, answering all questions.

To compensate for the unexpected access rates in phase one, the number of participating clinics planned for phase two was increased. Based on attendance rates, 700 patients had been considered eligible (50 at each of 14 clinics). The actual uptake was less than expected: 157 patients were directed to the amniocentesis web tool and 36 patients were directed to the breast cancer tool (data were only available from four of the seven breast clinics) (Table 2). Data about the number of patients directed to the PSA website from primary care were not available.

Table 2 also describes considerable variation between clinics in the number of patients who accessed the tool. Three of the antenatal clinics had access rates of 60% or higher; all the other antenatal clinics had access rates of 28% or lower. Having gained access, 26/54 (48%) patients viewed the amniocentesis site for 30 minutes or more, indicating significant levels of interest after overcoming the access hurdle. These data suggest that high proportion of patients will potentially access and use decision support tools: how best to motivate professionals to direct patients to these interventions is a challenge.

Interviews with health professionals: During phases 1 and 2, 57 interviews were conducted with health care professionals, across all sites, (see Table 3). Interviews in phase 2 focused on examining reasons for the unexpected low number of patients directed to use the decision support tools and what steps might be helpful in embedding patient decision support into routine practice. Analysis of the interviews revealed overall resistance to directing patients to use decision support. This resistance arose from existing professional attitudes and to barriers arising from current organisational routines. Box 1 illustrates the main themes found in the data:

Box 1 Summary of thematic analysis

Theme	Summary
1. Limited motivation to use patient decision support	Low motivation for the intended role of patient decision was encountered, as illustrated by uncertain deployment of the tools in clinical pathways and low uptake
2. 'We already do shared decision making'	Strong perception that clinicians were already involving patients in decisions, therefore no perceived need to change or to adopt decision support by adapting pathways
3. Perceived patients' barriers to involvement in decision making	Clinicians cited barriers such as technical access problems and often saw patients as those that did not want to be involved in shared decision making or as those they felt had already accessed information on the internet
4. Organisational resistance to patient's involvement in decision making	External efficiency targets and health professionals' views about effective treatments were barriers

Theme 1 Limited motivation to use patient decision support

The majority of key professionals, specialists, nurses and managers, had been invited to brief introductions about the websites and had been sent an information pack. However, interviews revealed that many clinicians had not fully understood the intended role of the tools, often ascribed to difficulty attending key meetings. Delays in the launch of the tools meant that professionals had not seen the websites, and were therefore uncertain about the content and also where exactly to position them in their clinical pathways.

Ideally, decision support tools should be used by patients when diagnosis and treatment options are confirmed. In urology, this is after urine flow dynamics or biopsies have provided a diagnosis; in knee clinics, this is after osteoarthritis has been confirmed as the likely cause of pain. However, many clinicians saw these tools as means for providing information and not as ways of engaging patients in treatment discussions, provided they did not disrupt clinical workflows. Clinicians reported being happy with: "*… anything that makes the patient genuinely more knowledgeable …"* (orthopaedic surgeon, site 3, phase 1) but the concept that patients should use these tools to engage in decisions was not widely understood: *"Having a summary sheet is fine for the patient but don't expect me to use it … it would interfere with what I do, although I can see it might lead to less questions – which is good"* (orthopaedic surgeon, site 2, phase 1).

Theme 2 'We already do shared decision making'

The interviews revealed a widely held belief that decisions were already shared with patients and that this was occurring without the need for patient decision support. As one nurse commented*, "I don't know how much more they could be involved [in decisions]"* (antenatal screening nurse, clinic 7). An antenatal specialist stated that: *"… we moved away from the patriarchal ideal of telling people what to do 20 years ago"* (specialist, clinic 7). Many clinicians espoused the view that: *"... you wouldn't replace the time you spend with patients by giving them a decision tool … and the shared decision making process … isn't dependent on having this kind of tool"* (breast care nurse, clinic 4).

Theme 3 Perceived patient barriers to involvement in decision making

Patients' inability to access the Internet was often raised. *"You wonder if they've got access, especially to broadband ..."* (specialist nurse, site 4, phase 1) and that: *"This generation are not used to getting information in this way"* (specialist nurse, site 6, phase 1). Clinicians also gave examples of patients resisting involvement in decisions. A surgeon reported one woman saying, *"I'll do whatever you say. You tell me to have a mastectomy, I'll have a mastectomy …"* (breast surgeon, clinic 4). A breast care nurse commented, *"... most women… say 'you make the decision for me … it's much easier if you tell me what I have to have done'"* (breast care nurse, clinic 4). Patients were often categorised as either "sufficiently informed" or misinformed, "*clutching internet printouts*" (breast surgeon, clinic 3). The prevailing view among interviewees was to accept, that, *"there is a role for your website but that cohort is very narrow ..."* (breast surgeon, clinic 1).

Theme 4 Organisational resistance to patient's involvement in decision making

External targets were often cited as barriers. Meeting efficiency targets, particularly in cancer, led to constant pressures. As a specialist explained, the constant pressure to *"get to a decision*" quickly means that clinicians do not *"… want to encourage indecisive patients go off* [to read a web tool]*, and then … come back and see us for another consultation"* (breast surgeon, clinic 1).

Many clinicians were explicit that they would not direct patients to tools that do not support their own views about effective treatments. For example, the breast cancer tool lists mastectomy and breast conservation surgery as treatments that should both be given consideration by women who have early breast cancer. Yet, many clinics have a different ethos. As one surgeon stated: *"We obviously try to do breast conservation whenever we can. That's the basic premise…"* (breast surgeon, clinic 1). This attitude is supported by external audits, where high mastectomy rates are viewed as inappropriate.

Routines were perceived as already being under pressure and so asking *"... a midwife to give [information about a web tool] was yet another thing …"* (antenatal screening coordinator, clinic 1). Existing processes were viewed as being satisfactory*: "I would say that what we're doing is actually fine"* (screening midwife, clinic 4) and that the website's *"information does not make women's decision about amniocentesis any easier"* (specialist, clinic 7). In short, it was felt that sufficient information was already available: most clinics did not see the websites as adding value to their work, and therefore saw no need for change. Nevertheless, three antenatal clinics achieved relatively high uptake rates, more importantly perhaps, access rates of 60% or higher (clinics 1, 6 and 7 – see Table 2). Interviews revealed that these three clinics had specifically modified their pathways and were alerting women by telephone about the tool at the same time as giving them their 'high risk' result and offer of amniocentesis. Women at clinic 7 were encouraged to access the website before attending their amniocentesis counselling session. Where the tools are integrated into routines, and expectations set that patients will use them before making decisions, different patterns of use emerge.

Patient interviews and survey

Ten patients in phase 1 volunteered for telephone interview (Table 3). These patients were positive about the balanced information about treatment options and were satisfied with the clarity of the website. Technical problems were confirmed. Patients also reported unmet expectations – that having become informed, it was disappointing to meet clinicians who were unwilling to involve them in decision making. In phase 1*,* 45 patients responded to the survey: 84% were very positive about the usefulness of the site, and 85% very positive about the ease of use, 76% were more positive about their upcoming outpatient appointment and 69% said that viewing had made a difference to their decision about treatment. In open comments, patients emphasised the advantage of being recommended high quality information that was available when it suited them, as one respondent said: "…*in my own time, in my own space and at my own pace"*. No volunteers for interviews or responses to surveys were received in phase 2.

Discussion

Principal Findings: This evaluation demonstrates that the implementation of patient decision support into routine practice is unlikely to be accomplished by the development of web-based tools alone: the relatively low uptake of the tools was explained by clinicians' uncertainty about the content and also where exactly to position them in their clinical pathways, their perception that 'shared decision making' was already commonplace in their teams. A minority also felt that patients, on the whole, are resistant to engaging in decisions. In addition, there was evidence that external factors, such as efficiency targets and 'best practice' recommendations, are viewed as have more influence in driving decisions than the informed preferences of patients.

In short, clinicians did not feel the need to direct patients to use decision support tools, web-based or not, and, as a result, felt no requirement to change existing routines. Taken together, these views represent significant barriers and explain why, in most of the clinics, few patients were directed to use the tools.

It was encouraging however to notice that the data revealed that many patients, when directed to these tools, are willing to use them and find them helpful. Uptake is highest when clinicians set expectations that these tools are integral to practice and embed their use into clinical pathways.

Strengths and weakness of methods: The strengths of the study are the pragmatic use of routine NHS settings, the purposive sampling of those who had been tasked to introduce patients to these web-based decision support tools and the use of web server logs to track access – so that actual use of the tools could be tracked. Constraints were placed on the evaluation processes by the tight service delivery timetables imposed by the NHS sponsor.

Although relevant clinicians were interviewed in all sites, the sample could have been expanded if more time had been available. A weakness of the study is the lack of patient interviews in the second evaluation phase, attributable to low uptake of the tools. Although the study sheds some light on some the implementation barriers, further work is needed into understand how to identify patients that would benefit from being asked to use decision support, i.e. to determine the eligible numbers in any given clinical pathway as a way of establishing the denominator population for assessing uptake.

Results in context of other similar work: Previous work on web-based patient decision support interventions has been typically undertaken in the context of randomised trials (1) and so it is difficult to draw comparisons to this pragmatic implementation study. Nevertheless, existing research studies do illustrate high degrees of difficulty in recruiting patients to use web-based interventions, even with dedicated resources and incentives (10)(11)(12). Holmes Rovner documented a decade ago that engaging clinicians to direct patients to use decision support tools active participants was a significant barrier to implementation (13). Caldon also documented of the concerns and anxieties of health professionals about patient decision support, such as the threat to clinical autonomy, the fear of more demanding patients and suspicion that the content was did not accord with their personal practice (4). These findings are echoed by recent reviews (14)(6)(15).

*Implications***:** As recently noted by Coulter (7), addressing the implementation challenge will require efforts targeted at changing hearts, minds and systems. More preparation and training might be helpful but future work will also need to work on achieving organisation-wide agreement about the role of these interventions and their location in clinical pathways.

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Contributorship: GE and AR designed the evaluation; AR and DJ undertook the interviews and conducted the qualitative analysis. TH undertook the quantitative analysis of the web log data. GE drafted the manuscript and is the guarantor and all authors contributed to the writing and editing process.

Data sharing: There is no additional data available.

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Table 1 Web-based patient decision support on NHS Direct

Phase 1	**Reasonable options considered**	**Evaluation Period**
Osteoarthritis (OA) of the knee (Sites 1, 2 and 3)	Pain management, lifestyle change, manual therapy, joint injections, knee replacement	June – August 2010
Benign Prostatic Hyperplasia (BPH) (sites 4,5,6,7,8)	Active monitoring, surgical approaches, medication	
Localised Prostate Cancer (LPC) (sites 4,5,6,7,8)	Active monitoring, surgical approaches, medication	
Phase 2		
Amniocentesis (based on AmnioDex) (16)	No test, amniocentesis, chorionic villus sampling	February – April 2011
Breast Cancer (based on BresDex) (17)	Breast conservation surgery (lumpectomy) or mastectomy	
Test for prostate specific antigen (PSA) (based on ProsDex) (12)	No test, PSA test	

Table 2 **Patients use of the web-tools during phases 1 and 2**

	Number of patients directed	Number of patients accessing	Number using web tool for > 30 minutes
Clinics in Phase 1 §			
Osteoarthritis (OA) of the knee, (Sites 1, 2 and 3)	162	102 (63%)	26 (16%)
Urology: Benign Prostatic Hyperplasia (sites 4,5,6,7,8)	Not known	8	2
Urology: Localised Prostate Cancer (sites 4,5,6,7,8)	Not known	24	5
Clinics in Phase 2			
1 Amniocentesis	32	20 (63%)	11 (55%)
2 Amniocentesis	25	3 (12%)	1 (33%)
3 Amniocentesis	25	3 (12%)	1 (33%)
4 Amniocentesis	32	9 (28%)	4 (44%)
5 Amniocentesis	20	3 (15%)	1 (33%)
6 Amniocentesis	10	6 (60%)	3 (50%)
7 Amniocentesis	13	10 (77%)	5 (50%)
All antenatal clinics	**157**	**54/157 (34%)**	**26/54 (48%)**
1 Breast cancer	12	1 (8%)	1 (100%)
2 Breast cancer	20	0 (0%)	Not applicable
3 Breast cancer	2	0 (0%)	Not applicable
4 Breast cancer	2	0 (0%)	Not applicable
5 Breast cancer	Unknown	2	2 (100%)
6 Breast cancer	Unknown	0	Not applicable
7 Breast cancer	Unknown	1	0 (0%)
All breast cancer clinics	**36**	**4/36 (11%)**	**3/4 (75%)**

§ In phase 1, numbers are aggregated.

Table 3 **Interviews undertaken for each intervention**

	Number healthcare professionals interviewed	Number of patients interviewed
Intervention		
Osteoarthritis of the knee	6	6
Benign Prostatic Hyperplasia	4	1
Localised Prostate Cancer	5	3
Amniocentesis	19	0
Breast Cancer	23	0
Prostate Specific Antigen	0	0
Total	**57**	**10**

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Why clinicians don’t refer patents to online decision support tools? Interviews from front line clinics in the NHS.

Glyn Elwyn, Andrew Rix, Tom Holt, Deborah Jones

Cochrane Institute of Primary Care and Public Health
Neuadd Meirionydd
School of Medicine
Cardiff University
Heath Park
United Kingdom
CF14 4YS

Glyn Elwyn, professor, elwyng@cardiff.ac.uk
Andrew Rix, independent researcher, andrewrixhome@gmail.com
Tom Holt, independent researcher, tbholt1@gmail.com
Deborah Jones, independent researcher, deb.jns64@gmail.com

Address for correspondence: Glyn Elwyn - glynelwyn@gmail.com

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All authors have completed the Unified Competing Interest form http://www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work [or describe if any]; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years [or describe if any], no other relationships or activities that could appear to have influenced the submitted work [or describe if any].

Summary

Focus

- Research studies demonstrate that engaging patients in the use of decision support (decision aids) is beneficial but there are significant challenges to their implementation into practice
- Clinicians are in a position to advocate the use of patient decision support but do not appear to do so.

Key messages

- Reluctance to refer patients to decision support is largely based on the scepticism of professionals that these tools add value, coupled with difficulties of incorporating the tools into existing workflows and competing organisational pressures, such as targets
- This reluctance will not be overcome simply by placing tools on the web
- When appropriately directed, a significant number of patients do use the decision support and say they find them useful.

Strengths and Limitations

- The evaluation study upon which these results are based set out to explore patterns of usage but turned to examine why take up was lower than expected
- The evidence comes mainly from 57 qualitative interviews with healthcare professionals taking part in the introduction of six web-based decision support tools hosted on the NHS Direct website

Abstract

Objective: To assess whether clinical teams would direct patients to use web-based patient decision support interventions (DESIs) and whether patients would use them.

Design: Retrospective semi-structured interviews and web server log analysis.

Participants and settings: 57 NHS professionals (nurses, doctors and others) in orthopaedic, antenatal, breast, urology clinics and in primary care practices across 22 NHS sites given access to DESIs hosted on the NHS Direct web-site.

Results: Fewer than expected patients were directed to use the web tools. The most significant obstacles to referral to the tools were the attitudes of clinicians and clinical teams Technical problems contributed to the problems but the low uptake was mainly explained by clinicians' limited understanding of how patient DESIs could be helpful in clinical pathways, their perception that 'shared decision making' was already commonplace and that, in their view, some patients are resistant to being involved in treatment decisions. External factors, such as efficiency targets and 'best practice' recommendations were also cited being significant barriers. Clinicians did not feel the need to refer patients to use decision support tools, web-based or not, and, as a result, felt no requirement to change existing practice routines. Uptake is highest when clinicians set expectations that these tools are integral to practice and embed their use into clinical pathways.

Conclusions: Existing evidence of patient benefit and the free availability of patient DESIs via the web are not sufficient drivers to achieve routine use. Health professionals were not motivated to refer patients to these interventions. Clinicians will not use these interventions simply because they are made available, despite good evidence of benefit to patients. These attitudes are deep seated and will not be modified by solely developing web-based interventions: a broader strategy will be required to embed DESIs into routine practice.

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Introduction

Are clinical teams willing to ask patients to use decision support interventions, when hosted on the web? A decade of research has demonstrated consistent positive outcomes when patient decision support interventions, often called decision aids, are evaluated in randomised controlled trials (1). Use of these interventions is advocated in order to help achieve shared decision making – where patients and clinicians work together to arrive at decisions that best match the informed patient preference (2). These interventions typically consider clinical situations where there are reasonable alternatives. Typical examples are whether to proceed to a total knee replacement or use alternative treatments or whether to accept or decline an amniocentesis, a procedure that runs the risk of leading to a miscarriage. When these interventions are used, patient knowledge increases, risk perceptions are more accurate, patients feel more actively involved in decisions and often tend to make more conservative choices, especially when considering discretionary surgery (1).

Despite good evidence and increasing policy support, studies have revealed resistance to the implementation of shared decision making and decision support (3). Professionals often hold the view that they 'already do' shared decision making, that the interventions promoted lack applicability to individual patients and that there is insufficient time to involve patients in decisions (4). To date, only a few studies have addressed the use of implementing these interventions in routine clinical settings (5). Many obstacles have been described and it is too early to say whether the benefits observed in randomised trials can be replicated (6). As yet, there has been no large scale study to assess the uptake possible in pragmatic settings (7).

Responding to the potential benefits of shared decision making and the use of patient decision support, the NHS in England invested approximately £1.5M in 2009-10 creating a platform of web-based patient decision support, as part of an England-wide shared decision making programme. NHS Direct was commissioned by the East of England Strategic Health Authority to adapt, host and pilot the introduction of web-based decision support interventions into the NHS, as part of the Quality Innovation, Performance and Prevention Programme.

A multi-phase programme of work was proposed, with the aim of creating an easily accessed web-based set of patient decision support tools hosted on an NHS web-platform coupled with telephone support (2). An external evaluation was set up to assess whether clinical teams would direct patients to these tools and to assess uptake and use. This article reports on the attitudes of participating staff which lie behind the reluctance to refer patients to these tools.

Methods

Two phases were planned. In each phase, three web interventions were adapted and hosted on NHS Direct's website. NHS sites were recruited into evaluation pilots of approximately three-month's duration – see Table 1.

In phase 1, the three interventions were adaptations of programmes originally developed by the Foundation for Informed Decision Making, Boston (see Table 1). The prostate web interventions were originally produced in DVD versions and had been previously introduced into some clinics in England (8)(9).

Eight NHS clinics, across England, some with previous involvement in the development of the DVD and web-based versions, agreed to introduce patients to them. For the knee condition, patients referred to secondary care were identified by staff and directed to access the web-based tools to read information about a range of treatment options, e.g. physiotherapy, injections and knee replacement. If patients completed the use of the web tool, a personalised summary was generated that listed their preferred treatment. Patients were asked to either print this summary or, when they attended their next clinic appointment, to ask for the summary to be discussed with them. It had been estimated that 360 patients across three clinics would be eligible to use the knee osteoarthritis web intervention during the evaluation period. Similar methods were applied to the web tools for BHP and LPC.

In phase 2, three interventions were adapted from tools developed at Cardiff University (Table 1). Data was collected from 7 breast cancer and 7 antenatal outpatient clinics recruited by NHS Direct (Table 2). Estimates of patients potentially eligible for these tools had been set at 50 per site, a pool of around 700 patients. Primary Care Trusts in England were asked to contact primary care practices, alerting clinicians to the availability of the PSA decision support tool.

Data Collection

Data was collected in each phase for a maximum of 14 weeks using the following methods:

Referral data: In both phases, clinics kept a record of patients directed to use the tools. Patients were given unique access codes, enabling anonymised tracking of server web logs.

Web logs: web server log data was collected, tracking access (content and duration) of each web page viewed.

Interviews with health professionals: After informed consent was obtained, semi-structured interviews were conducted with medical and nursing specialists responsible for implementing the intervention at each clinic. The respondents were asked their views about the web-based patient decision support and whether they had referred patients to them, we asked about the role they might play in their work. Interviews were conducted at the start, mid-point and end of the pilots, audio-recorded and transcribed. Results from the evaluation of the first phase led to a change of focus for the evaluation of the second phase.

Data analysis: Web server log data were verified, cleaned and analysed by TH. AR and DJ coded the interviews independently, meeting to agree coding frames, prior to jointly categorising the data into themes related to clinician views about the decision support tools and their willingness to direct patients to them.

Results

Patient's access and use: Records indicate that 162 of the estimated potential pool of 360 patients were offered access to the OA knee tool: 102 of the 162 visited (63%) visited the site, at least briefly. A total of 38 (23%) provided some information; 27 patients (26%) used the site in sufficiently to produce a summary sheet that could be used in a future clinic appointment. This number represents 7% of those estimated to have been eligible. No estimates were available for eligible patients in relation to BPH and LPC, or for numbers directed to the sites. Web log data showed 24 and 8 unique visitors to the LPC and BPH sites respectively, resulting in 5 and 2 patients using the sites from introductory pages to summary page, answering all questions.

To compensate for the unexpected access rates in phase one, the number of participating clinics planned for phase two was increased. Based on attendance rates, 700 patients had been considered eligible (50 at each of 14 clinics). The actual uptake was less than expected: 157 patients were directed to the amniocentesis web tool and 36 patients were directed to the breast cancer tool (data were only available from four of the seven breast clinics) (Table 2). Data about the number of patients directed to the PSA website from primary care were not available.

Table 2 also describes considerable variation between clinics in the number of patients who accessed the tool. Three of the antenatal clinics had access rates of 60% or higher; all the other antenatal clinics had access rates of 28% or lower. Having gained access, 26/54 (48%) patients viewed the amniocentesis site for 30 minutes or more, indicating significant levels of interest after overcoming the access hurdle. These data suggest that high proportion of patients will potentially access and use decision support tools: how best to motivate professionals to direct patients to these interventions is a challenge.

Interviews with health professionals: During phases 1 and 2, 57 interviews were conducted with health care professionals, across all sites, (see Table 3). Interviews in phase 2 focused on examining reasons for the unexpected low number of patients directed to use the decision support tools and what steps might be helpful in embedding patient decision support into routine practice. Analysis of the interviews revealed overall resistance to directing patients to use decision support. This resistance arose from existing professional attitudes and to barriers arising from current organisational routines. Box 1 illustrates the main themes found in the data:

Box 1 Summary of themes derived from the qualitative analysis

Theme	Summary
1. Limited motivation to use patient decision support	Low motivation for the intended role of patient decision was encountered, as illustrated by uncertain deployment of the tools in clinical pathways and low uptake by patients
2. 'We already do shared decision making'	Strong perception that clinicians were already involving patients in decisions, therefore no perceived need to change or to adopt decision support by adapting pathways
3. Perceived patients' barriers to involvement in decision making	Clinicians cited barriers such as technical access problems and often saw patients as those that did not want to be involved in shared decision making or as those they felt had already accessed information on the internet
4. Organisational resistance to patient's involvement in decision making	External efficiency targets and health professionals' views about effective treatments were barriers

Theme 1 Limited motivation to use patient decision support

The majority of key professionals, specialists, nurses and managers, had been invited to brief introductions about the websites and had been sent an information pack. However, interviews revealed that many clinicians had not fully understood the intended role of the tools. Ideally, decision support tools should be used by patients when diagnosis and treatment options are confirmed. In urology, this is after urine flow dynamics or biopsies have provided a diagnosis; in knee clinics, this is after osteoarthritis has been confirmed as the likely cause of pain. However, many clinicians saw these tools as merely means for providing information and not as ways of engaging patients in discussions about treatment decisions. Clinicians reported being happy with: "*… anything that makes the patient genuinely more knowledgeable …" (*orthopaedic surgeon, site 3, phase 1*).* However, the concept that patients should use these tools to engage in decisions was not widely understood: *"Having a summary sheet is fine for the patient but don't expect me to use it … it would interfere with what I do, although I can see it might lead to less questions – which is good"* (orthopaedic surgeon, site 2, phase 1).

Theme 2 'We already do shared decision making'

The interviews revealed a widely held belief that decisions were already shared with patients and that this was occurring without the need for patient decision support. As one nurse commented*, "I don't know how much more they could be involved [in decisions]"* (antenatal screening nurse, clinic 7). An antenatal specialist stated that: *"… we moved away from the patriarchal ideal of telling people what to do 20 years ago"* (specialist, clinic 7). Many clinicians espoused the view that: *"... you wouldn't replace the time you spend with patients by giving them a decision tool … and the shared decision making process … isn't dependent on having this kind of tool"* (breast care nurse, clinic 4).

Theme 3 Perceived patient barriers to involvement in decision making

Patients' inability to access the Internet was often raised. *"You wonder if they've got access, especially to broadband ..."* (specialist nurse, site 4, phase 1) and that: *"This generation are not used to getting information in this way"* (specialist nurse, site 6, phase 1). Clinicians also gave examples of patients resisting involvement in decisions. A surgeon reported one woman saying, *"I'll do whatever you say. You tell me to have a mastectomy, I'll have a mastectomy …"* (breast surgeon, clinic 4). A breast care nurse commented, *"... most women… say 'you make the decision for me … it's much easier if you tell me what I have to have done'"* (breast care nurse, clinic 4). Patients were often categorised as either "sufficiently informed" or misinformed, "*clutching internet printouts*" (breast surgeon, clinic 3). The prevailing view among interviewees was to accept, that, *"there is a role for your website but that cohort is very narrow ..."* (breast surgeon, clinic 1).

Theme 4 Organisational resistance to patient's involvement in decision making

External targets were often cited as barriers. Meeting efficiency targets, particularly in cancer, led to constant pressures. As a specialist explained, the constant pressure to *"get to a decision*" quickly means that clinicians do not *"… want to encourage indecisive patients go off* [to read a web tool]*, and then … come back and see us for another consultation"* (breast surgeon, clinic 1).

Many clinicians were explicit that they would not direct patients to tools that do not support their own views about effective treatments. For example, the breast cancer tool lists mastectomy and breast conservation surgery as treatments that should both be given consideration by women who have early breast cancer. Yet, many clinics have a different ethos. As one surgeon stated: *"We obviously try to do* *breast conservation whenever we can. That's the basic premise…"* (breast surgeon, clinic 1). This attitude is supported by external audits, where high mastectomy rates are viewed as inappropriate.

Routines were perceived as already being under pressure and so asking *"... a midwife to give [information about a web tool] was yet another thing …"* (antenatal screening coordinator, clinic 1). Existing processes were viewed as being satisfactory*: "I would say that what we're doing is actually fine"* (screening midwife, clinic 4) and that the website's *"information does not make women's decision about amniocentesis any easier"* (specialist, clinic 7). In short, it was felt that sufficient information was already available: most clinics did not see the websites as adding value to their work, and therefore saw no need for change. Nevertheless, three antenatal clinics achieved relatively high uptake rates, more importantly perhaps, access rates of 60% or higher (clinics 1, 6 and 7 – see Table 2). Interviews revealed that these three clinics had specifically modified their pathways and were alerting women by telephone about the tool at the same time as giving them their 'high risk' result and offer of amniocentesis. Women at clinic 7 were encouraged to access the website before attending their amniocentesis counselling session. Where the tools are integrated into routines, and expectations set that patients will use them before making decisions, different patterns of use emerge.

Discussion

Principal Findings: This evaluation demonstrates that the implementation of patient decision support into routine practice is unlikely to be accomplished by the development of web-based tools alone: the relatively low uptake of the tools was explained by clinicians' uncertainty about the content and also where exactly to position them in their clinical pathways, their perception that 'shared decision making' was already commonplace in their teams. A minority also felt that patients, on the whole, are resistant to engaging in decisions. In addition, there was evidence that external factors, such as efficiency targets and 'best practice' recommendations, are viewed as have more influence in driving decisions than the informed preferences of patients.

In short, clinicians did not feel the need to direct patients to use decision support tools, web-based or not, and, as a result, felt no requirement to change existing routines. Taken together, these views represent significant barriers and explain why, in most of the clinics, few patients were directed to use the tools.

It was encouraging however to notice that the data revealed that many patients, when directed to these tools, are willing to use them. Uptake is highest when clinicians set expectations that these tools are integral to practice and embed their use into clinical pathways.

Strengths and weakness of methods: The strengths of the study are the pragmatic use of routine NHS settings, the purposive sampling of those who had been actually tasked to introduce patients to these web-based decision support tools. The use of web server logs to track access provides direct data about the actual use of the tools. Constraints were placed on the intensity of the evaluation processes by the tight service delivery timetables set by the NHS sponsor.

Although relevant clinicians were interviewed in all sites, the sample could have been expanded if more time had been available. Although the study sheds some light on some the implementation barriers, further work is needed into understand how to identify patients that would benefit from being asked to use decision support, i.e. to determine the eligible numbers in any given clinical pathway as a way of establishing the denominator population for assessing uptake.

Results in context of other similar work: Previous work on web-based patient decision support interventions has been typically undertaken in the context of randomised trials (1) and so it is difficult to draw comparisons to this pragmatic implementation study. Nevertheless, existing research studies do illustrate high degrees of difficulty in recruiting patients to use web-based interventions, even with dedicated resources and incentives (10)(11)(12). Holmes Rovner documented a decade ago that engaging clinicians to direct patients to use decision support tools active participants was a significant barrier to implementation (13). Caldon also documented of the concerns and anxieties of health professionals about patient decision support, such as the threat to clinical autonomy, the fear of more demanding patients and suspicion that the content was did not accord with their personal practice (4). These findings are echoed by recent reviews (14)(6)(15).

*Implications***:** As recently noted by Coulter (7), addressing the implementation challenge will require efforts targeted at changing hearts, minds and systems. More preparation and training might be helpful but future work will also need to work on achieving organisation-wide agreement about the role of these interventions and their location in clinical pathways.

Funding and Ethical Approval: NHS Direct were commissioned by the East of England Strategic Health Authority to adapt, host and evaluate the use of patient decision support in England. NHS Direct provided funding for the evaluation, considered the evaluation under their research governance process and given the service evaluation nature of the study, decided that ethical approval was not required. NHS Direct had no involvement in the drafting of this article.

Acknowledgements: We acknowledge the support and advice of the following people. Marie Anne Durand, at the time Programme Manager of the UK SDM Programme, Steven Laitner, SDM Programme Lead, Nick Chapman, Chief Executive Officer NHS Direct and Shirley Large, Head of Research NHS Direct.

Contributorship: GE and AR designed the evaluation; AR and DJ undertook the interviews and conducted the qualitative analysis. TH undertook the quantitative analysis of the web log data. GE drafted the manuscript and is the guarantor and all authors contributed to the writing and editing process.

Data sharing: There is no additional data available.

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Table 1 Web-based patient decision support hosted on NHS Direct

Phase 1	**Reasonable options considered**	**Evaluation Period**
Osteoarthritis (OA) of the knee (Sites 1, 2 and 3)	Pain management, lifestyle change, manual therapy, joint injections, knee replacement	June – August 2010
Benign Prostatic Hyperplasia (BPH) (sites 4,5,6,7,8)	Active monitoring, surgical approaches, medication	
Localised Prostate Cancer (LPC) (sites 4,5,6,7,8)	Active monitoring, surgical approaches, medication	
Phase 2		
Amniocentesis (based on AmnioDex) (16)	No test, amniocentesis, chorionic villus sampling	February – April 2011
Breast Cancer (based on BresDex) (17)	Breast conservation surgery (lumpectomy) or mastectomy	
Test for prostate specific antigen (PSA) (based on ProsDex) (12)	No test, PSA test	

Table 2 **Patients use of the web-tools during phases 1 and 2**

	Number of patients directed	Number of patients accessing	Number using web tool for > 30 minutes
Clinics in Phase 1 §			
Osteoarthritis (OA) of the knee, (Sites 1, 2 and 3)	162	102 (63%)	26 (16%)
Urology: Benign Prostatic Hyperplasia (sites 4,5,6,7,8)	Not known	8	2
Urology: Localised Prostate Cancer (sites 4,5,6,7,8)	Not known	24	5
Clinics in Phase 2			
1 Amniocentesis	32	20 (63%)	11 (55%)
2 Amniocentesis	25	3 (12%)	1 (33%)
3 Amniocentesis	25	3 (12%)	1 (33%)
4 Amniocentesis	32	9 (28%)	4 (44%)
5 Amniocentesis	20	3 (15%)	1 (33%)
6 Amniocentesis	10	6 (60%)	3 (50%)
7 Amniocentesis	13	10 (77%)	5 (50%)
All antenatal clinics	**157**	**54/157 (34%)**	**26/54 (48%)**
1 Breast cancer	12	1 (8%)	1 (100%)
2 Breast cancer	20	0 (0%)	Not applicable
3 Breast cancer	2	0 (0%)	Not applicable
4 Breast cancer	2	0 (0%)	Not applicable
5 Breast cancer	Unknown	2	2 (100%)
6 Breast cancer	Unknown	0	Not applicable
7 Breast cancer	Unknown	1	0 (0%)
All breast cancer clinics	**36**	**4/36 (11%)**	**3/4 (75%)**

§ In phase 1, numbers are aggregated.

Table 3 **Interviews undertaken for each intervention**

	Number healthcare professionals interviewed
Intervention	
Osteoarthritis of the knee	6
Benign Prostatic Hyperplasia	4
Localised Prostate Cancer	5
Amniocentesis	19
Breast Cancer	23
Prostate Specific Antigen	0
Total	**57**

Tuesday, 18 September 12

Dear Mr Sands
We have revised the article as requested.
We have addressed the very helpful comments of reviewer Johnston as follows:

1. What were the questions asked?

Response: We have clarified the questions we asked in the following paragraph:

Interviews with health professionals: After informed consent was obtained, semi-structured interviews were conducted with medical and nursing specialists responsible for implementing the intervention at each clinic. The respondents were asked their views about the web-based patient decision support and whether they had referred patients to them, we asked about the role they might play in their work. Interviews were conducted at the start, mid-point and end of the pilots, audio-recorded and transcribed. Results from the evaluation of the first phase led to a change of focus for the evaluation of the second phase.

2. Concern re patient data and recruitment.

Response: We agree that the data from patients is not as clear and we have therefore removed all mention of patient level data in this article.

3. The English language writing needs improvement. Box and table labels should provide a more clear description of the content.

Response: We have edited the paper to improve and have added clearer labels on box and tables.

4. The title is poor and should be revised.

Response: We have changed the title to:

Why clinicians don’t refer patents to online decision support tools? Interviews from front line clinics in the NHS.

5. Other issues raised.

Response: We feel the reviewer has not appreciated that this was a pragmatic evaluation of a rapidly introduced set of NHS Direct web based tools. We were able to conduct qualitative semi-structured interviews with 57 NHS staff and the data are derived from these interviews. Coupled with the low patient visits to the online tools, we are confident that we are representing the challenges of implementing web-based decision support tools for patients.

Response to reviewer Bennert that there was low uptake of the intervention and that patient recruitment was lacking.

1. I also agree with the authors' position that lack of interest by clinicians to be actively involved in this kind of research is itself a finding worth reporting.

Our response: we agree – and especially as they were volunteer clinics. The reaction in clinics that did not self-select to take part in such studies might be even more challenging. We do not now mention the patient level data and agree that is not robust enough to be included.

2. The research question was adapted in light of the poor referral and response rates. The findings confirm some of the known barriers to the implementation of DESIs. However the presentation of the findings from thematic analysis of interview data in the results section is poorly presented and organised in my view. Anaysis stays descriptive and superficial and does not probe sufficiently into connections between themes. Some of the data extracts don't match well with the thematic headings under which they are discussed. For example, under theme 2: 'we already do sdm', clinicians seem to raise concerns about the extent to which genuine involvement is possible/desirable and the trade off between time spent with a tool vs time spent with clinicians. Perceptions of DESIs as complements vs replacements of consultation time would have been interesting to explore further here. Similarly, the theme 'organisational resistance' is too broad to be genuinely informative and glosses over the very different ethical and organisation concerns in different healthcare contexts that may prevent clinicians from fully emrbacing DESIs in their practice. The iauthors' interpretations in my view are not sufficeintly grounded in the data presented. While I realise this may be partly due to space restrictions it is probably also a consequence of trying to generalise from a wide range of different clincial perspecitves and contexts, at the cost of uncovering the more complex issues that may prevent referral and uptake of DESIs in each setting.

Our response: We have worked to tie the themes to the data. See examples in para below that show that the clinicians believe they are already providing patients with the opportunity to be engaged in decisions. Parallel literature from the patient perspective indicates clearly that patients do not share these views and wish to have both more information and more involvement in dec

Theme 2 ‘We already do shared decision making’

The interviews revealed a widely held belief that decisions were already shared with patients and that this was occurring without the need for patient decision support. As one nurse commented*, "I don't know how much more they could be involved [in decisions]"* (antenatal screening nurse, clinic 7). An antenatal specialist stated that: *"… we moved away from the patriarchal ideal of telling people what to do 20 years ago"* (specialist, clinic 7). Many clinicians espoused the view that: *"… you wouldn't replace the time you spend with patients by giving them a decision tool … and the shared decision making process … isn't dependent on having this kind of tool"* (breast care nurse, clinic 4).

> After all, 'limited motivation' as a theme does not really explain anything! On the other hand, the amniocentesis intervention appears as a 'deviant case' with far better referral and uptake than the other interventions, so it would have been desirable to explore in greater depth what were the facilicating factors in this context. In short, I feel that by spreading their analysis very thinly across so many different healthcare contexts, the authors have robbed themselves of the chance to say something novel and more informative about barriers to the use of DESis in specific contexts. None of the themes are surprising but they are insufficeintly elaborated to form a basis for key messages about how to tackle change.

Our response: We have worked to give our analysis more depth and have included more relevant quotes. We disagree that we are not saying anything novel. Very few studies have reported real life efforts to implement web-based tools (we have reviewed them all (article under review) and cite that in this new version.

Dear Dr. Elwyn:

Manuscript ID bmjopen-2012-001530 entitled "Why don't NHS healthcare professionals recommend patients use web-based decision support tools? Interviews from the front line." which you submitted to BMJ Open, has been reviewed. The comments of the reviewer(s) are included at the bottom of this letter.

The reviewer(s) have recommended revisions to your manuscript. Therefore, I invite you to respond to the reviewer(s)' comments and revise your manuscript. Please remember that the reviewers' comments and the previous drafts of your manuscript will be published as supplementary information alongside the final version.

To revise your manuscript, log into http://mc.manuscriptcentral.com/bmjopen and enter your Author Center, where you will find your manuscript title listed under

"Manuscripts with Decisions." Under "Actions," click on "Create a Revision." Your manuscript number has been appended to denote a revision.

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Sincerely,
Mr. Richard Sands
Managing Editor, BMJ Open
rsands@bmjgroup.com

Reviewer(s)' Comments to Author:

Reviewer: Janice Johnston
Associate Professor

School of Public Health
University of Hong Kong
Hong Kong
I have no competing interests

The participants are not described except in very general terms. What is the age, gender, years of experience of the clinical staff/patients? Who are the interviewed clinical staff? This should be in a table form.

The guided interview questions should be included. How were the questions derived - ie. What informed these research questions?
What is the format of the web log data. How accurate is this data? How could this data be used as an alternative outcome variable?
How were patients recruited? As patients from phase 2 were not recruited - the study is incomplete and the reliability of the conclusions drawn very limited. This is a 'failed' process and as such may be very informative for future research. This should be fully discussed and the limitations clarified. The authors should provide concrete suggestions on how to improve the recruitment in future work of this type. \
How were the surveys constructed and validated? - If not validated this raises a significant scientific criticism for this study.

The english language writing needs improvement. Box and table labels should provide a more clear description of the content.

The title is poor and should be revised.

Given the methodological problems - the results are not able to answer the research question except in the negative and may not be credible. This should be fully discussed.
In some qualitative papers the results and discussion sections are merged. This would be appropriate for this paper as the discussion section is somewhat repetitive of the results.
What is credible and trustworthy in a qualitative study? This needs to be discussed here and the authors need to provide justification as to why the results are valid and meaningful.
Prior research should inform the discussion of the results.

I am not sure if this is a major revision or a reject as it is unclear at present how the authors can address the comments above. I will leave this decision to the editors.

Reviewer: Dr Kristina Bennert
Senior Qualitative Researcher
Department of Primary Health Sciences
University of Oxford

and
Research Associate
School of Social and Community Medicine
University of Bristol
UK
no competing interests

This is a mixed methods study reporting clinician and patient views on DESIs in six different healthcare contexts. No statistical methods were used. Instead, numbers and percentages of patients directed to DESIs, accessing DESIs and using them for >30 min are reported.
The authors themselves highlight the difficulties they had in collecting qualitative interview data from clinicians and patients in a systematic fashion, so sampling was uneven and patchy. No patients were interviewed for 3 of the 6 examined contexts and no clinician views could be elicited for one condition. Exclusion/inclusion criteria are insufficiently described, e.g. not clear whether all patients referred or only those accessing/using were approached for interview, and which clinicians were approached/selected for interview and why. In the thematic analysis of the results section, quotes are mostly too short and insufficiently contextualised with the results of the overall analysis and participants are insufficiently identified to judge whether the articulated views can be regarded as representative for the health context or for clinicians'/patients' views of DESIs at large. While the study was well-designed, the poor response in my view has severely hampered the representativeness of the qualitative data obtained. However, I also agree with the authors' position that lack of interest by clinicians to be actively involved in this kind of research is itself a finding worth reporting.

The research question was adapted in light of the poor referral and response rates. The findings confirm some of the known barriers to the implementation of DESIs. However the presentation of the findings from thematic analysis of interview data in the results section is poorly presented and organised in my view. Anaysis stays descriptive and superficial and does not probe sufficiently into connections between themes. Some of the data extracts don't match well with the thematic headings under which they are discussed. For example, under theme 2: 'we already do sdm', clinicians seem to raise concerns about the extent to which genuine involvement is possible/desirable and the trade off between time spent with a tool vs time spent with clinicians. Perceptions of DESIs as complements vs replacements of consultation time would have been interesting to explore further here. Similarly, the theme 'organisational resistance' is too broad to be genuinely informative and glosses over the very different ethical and organisation concerns in different healthcare contexts that may prevent clinicians from fully emrbacing DESIs in their practice. The iauthors' interpretations in my view are not sufficeintly grounded in the data presented. While I realise this may be partly due to space restrictions it is probably also a consequence of trying to generalise from a wide range of different clincial perspecitves and contexts, at the cost of uncovering the more complex issues that may prevent referral and uptake of DESIs in each setting. After all, 'limited motivation' as a theme does not really explain anything! On the other hand, the amniocentesis intervention appears as a 'deviant case' with far better referral and uptake than the other interventions, so it would have been desirable to explore in greater depth what were the facilicating factors in this context. In short, I feel that by spreading their analysis very thinly across so many different healthcare contexts, the authors have robbed themselves of the chance to say something novel and more informative about barriers to the use of DESis in specific contexts. None of the themes are surprising but they are insufficeintly elaborated to form a basis for key messages about how to tackle change.

I think this is a very worthwhile and important study to publish. I have read it with great interest and hope that my comments will be helpful in sharpening the focus and explanatory power of the thematic analysis.

Why ~~don't NHS healthcare professionals~~clinicians don't refer ~~recommend~~ patents ~~use~~ to online~~web-based~~ decision support tools? Interviews from ~~the~~ front line clinics in the NHS~~front line~~.

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Glyn Elwyn, Andrew Rix, Tom Holt, Deborah Jones

Cochrane Institute of Primary Care and Public Health
Neuadd Meirionydd
School of Medicine
Cardiff University
Heath Park
United Kingdom
CF14 4YS

Glyn Elwyn, professor, elwyng@cardiff.ac.uk
Andrew Rix, independent researcher, andrewrixhome@gmail.com
Tom Holt, independent researcher, tbholt1@gmail.com
Deborah Jones, independent researcher, deb.jns64@gmail.com

Address for correspondence: Glyn Elwyn - glynelwyn@gmail.com

Keywords: patient decision support, decision aids, shared decision making, patient centred care, informed consent.

All authors have completed the Unified Competing Interest form http://www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work [or describe if any]; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years [or describe if any], no other relationships or activities that could appear to have influenced the submitted work [or describe if any].

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Summary

Focus

- Research studies demonstrate that engaging patients in the use of decision support (decision aids) is beneficial but there are significant challenges to their implementation into practice~~take up is low~~
- Clinicians are in a position to advocate the use of patient decision support ~~by~~ but do not appear to do so.

Key messages

- Reluctance to ~~point~~ refer patients ~~in the direction of~~to decision support is largely based on the scepticism of~~a complex mixture of~~ professionals that these tools add value, coupled with ~~attitudes,~~ difficulties ~~in~~ of incorporating the tools into existing work ~~patterns~~ flows and competing organisational pressures, such as targets
- This reluctance will not be overcome simply by ~~making~~ placing ~~more~~ tools ~~available and more accessible~~on the web
- When appropriately directed, a significant number of patients do use the decision support and say they find them useful.

Strengths and Limitations

- The evaluation study upon which these results are based set out to explore patterns of usage but turned to examine why take up was lower than expected
- The evidence comes mainly from 57 qualitative interviews with healthcare professionals taking part in the introduction of six web-based decision support tools hosted on the NHS Direct website
- ~~Low take-up reduced the opportunity to obtain evidence from patient users.~~

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Abstract

Objective: To assess whether clinical teams would direct patients to use web-based patient decision support interventions (DESIs) and whether patients would use them.

Design: ~~Mixed methods using concurrent and R~~retrospective semi-structured interviews and ~~,~~ web server log analysis.~~ and surveys.~~

Participants and settings: 57 NHS professionals (nurses, doctors and others) in orthopaedic, antenatal, breast, urology clinics and in primary care practices ~~and 10 patients~~ across 22 NHS sites given access to DESIs hosted on the NHS Direct web-site.

Results: Fewer than expected patients were directed to use the web tools. The most significant obstacles to referral to the tools were the attitudes of clinicians and clinical teams. Technical problems ~~partly~~ contributed to the problems but the low uptake was mainly explained by clinicians' limited understanding of how patient ~~they~~ DESIs ~~should~~ could be helpful ~~be located~~ in clinical pathways, their perception that 'shared decision making' was already commonplace and that, in their view, some patients are resistant to being involved in treatment decisions. External factors, such as efficiency targets and 'best practice' recommendations were also cited ~~as having a significant~~being significant barriers.~~ negative influence on clinicians' decisions to refer.~~ Clinicians did not feel the need to ~~direct~~ refer patients to use decision support tools, web-based or not, and, as a result, felt no requirement to change existing practice routines.~~. However, the data also showed that many patients, when directed to these tools, were willing to access and use them and found them helpful.~~ Uptake is highest when clinicians set expectations that these tools are integral to practice and embed their use into clinical pathways.

Conclusions: Existing evidence of patient benefit and the free availability of ~~from a Cochrane review and making~~patient DESIs ~~freely available~~ via the web are not sufficient drivers to ~~guarantee~~ achieve routine use. ~~Changes are needed in attitudes and skills as well as system support to reach organisation-wide agreement about the role of these interventions and their location in clinical pathways.~~Health professionals were not motivated to refer patients to these interventions. Clinicians will not use these interventions simply because they are made available, despite good evidence of benefit to patients. These attitudes are deep seated and will not be modified by solely developing web-based interventions: a broader strategy will be required to embed DESIs into routine practice.

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Introduction

Are clinical teams willing to ask patients to use decision support interventions, when hosted on the web? A decade of research has demonstrated consistent positive outcomes when patient decision support interventions, often called decision aids, are evaluated in randomised controlled trials (1). Use of these interventions is advocated in order to help achieve shared decision making – where patients and clinicians work together to arrive at decisions that best match the informed patient preference (2). These interventions typically consider clinical situations where there are reasonable alternatives. Typical examples are whether to proceed to a total knee replacement or use alternative treatments or whether to accept or decline an amniocentesis, a procedure that runs the risk of leading to a miscarriage. When these interventions are used, patient knowledge increases, risk perceptions are more accurate, patients feel more actively involved in decisions and often tend to make more conservative choices, especially when considering discretionary surgery (1).

Despite good evidence and increasing policy support, studies have revealed resistance to the implementation of shared decision making and decision support (3). Professionals often hold the view that they 'already do' shared decision making, that the interventions promoted lack applicability to individual patients and that there is insufficient time to involve patients in decisions (4). To date, only a few studies have addressed the use of implementing these interventions in routine clinical settings (5). Many obstacles have been described and it is too early to say whether the benefits observed in randomised trials can be replicated (6)~~(Francis Légaré et al., 2010).~~. As yet, there has been no large scale study to assess the uptake possible in pragmatic settings (7).

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Responding to the potential benefits of shared decision making and the use of patient decision support, the NHS in England invested approximately £1.5M in 2009-10 creating a platform of web-based patient decision support, as part of an England-wide shared decision making programme. NHS Direct was commissioned by the East of England Strategic Health Authority to adapt, host and pilot the introduction of web-based decision support interventions into the NHS, as part of the Quality Innovation, Performance and Prevention Programme.

A multi-phase programme of work was proposed, with the aim of creating an easily accessed web-based set of patient decision support tools hosted on an NHS web-platform coupled with telephone support (2). An external evaluation was set up to assess whether clinical teams would direct patients to these tools and to assess uptake and use. This article reports on the attitudes of participating staff which lie behind the reluctance to refer patients to these tools. ~~This article reports the main findings of the evaluation, based on web-server logs and interviews with clinical staff.~~

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Methods

Two phases were planned. In each phase, three web interventions were adapted and hosted on NHS Direct's website. NHS sites were recruited into evaluation pilots of approximately three-month's duration – see Table 1.

In phase 1, the three interventions were adaptations of programmes originally developed by the Foundation for Informed Decision Making, Boston (see Table 1). The prostate web interventions were originally produced in DVD versions and had been previously introduced into some clinics in England (8)(9).

Eight NHS clinics, across England, some with previous involvement in the development of the DVD and web-based versions, agreed to introduce patients to them. For the knee condition, patients referred to secondary care were identified by staff ~~at the relevant clinics~~ and directed to access the web-based tools to read information about a range of treatment options, e.g. physiotherapy, injections and knee replacement. If patients completed the use of the web tool, a personalised summary was generated that listed their preferred treatment. Patients were asked to either print this summary or, when they attended their next clinic appointment, to ask for the summary to be discussed with them. It had been estimated that 360 patients across three clinics would be eligible to use the knee osteoarthritis web intervention during the evaluation period. Similar methods were applied to the web tools for BHP and LPC.

In phase 2, three interventions were adapted from tools developed at Cardiff University (~~see~~ Table 1). Data was collected from 7 breast cancer and 7 antenatal outpatient clinics recruited by NHS Direct (Table 2). Estimates of patients potentially eligible for these tools had been set at 50 per site, a pool of around 700 patients. Primary Care Trusts in England were asked to contact primary care practices, alerting clinicians to the availability of the PSA decision support tool.

Data Collection

Data was collected in each phase for a maximum of 14 weeks using the following methods:

Referral data: In both phases, clinics kept a record of patients directed to use the tools. Patients were given unique access codes, enabling anonymised tracking of server web logs.

Web logs: web server log data was collected, tracking access (content and duration) of each web page viewed.

Interviews with health professionals: After informed consent was obtained, semi-structured interviews were conducted with medical and nursing specialists responsible for implementing the intervention at each clinic. The respondents were asked their views about the web-based patient decision support and whether they had referred patients to them, we asked about the the role they might play in their work. Interviews were conducted at the start, mid-point and end of the pilots, audio-recorded and transcribed. Results from the evaluation of the first phase led to a change of focus for the evaluation of the second phase.

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~~*Patient interviews and surveys*: Short survey tools addressed questions about usability and assessed knowledge about the relevant condition. Patients also consented to a semi-structured telephone interview about their experience of using the site.~~

Data analysis: Web server log data were verified, cleaned and analysed by TH. AR and DJ coded the interviews independently, meeting to agree coding frames, prior to jointly categorising the data into themes related to clinician views about the decision support tools and their willingness to direct patients to them.

Results

Patient's access and use: Records indicate that 162 of the estimated potential pool of 360 patients were offered access to the OA knee tool: 102 of the 162 visited (63%) visited the site, at least briefly. A total of 38 (23%) provided some information; 27 patients (26%) used the site in sufficiently to produce a summary sheet that could be used in a future clinic appointment. This number represents 7% of those estimated to have been eligible. No estimates were available for eligible patients in relation to BPH and LPC, or for numbers directed to the sites. Web log data showed 24 and 8 unique visitors to the LPC and BPH sites respectively, resulting in 5 and 2 patients using the sites from introductory pages to summary page, answering all questions.

To compensate for the unexpected access rates in phase one, the number of participating clinics planned for phase two was increased. Based on attendance rates, 700 patients had been considered eligible (50 at each of 14 clinics). The actual uptake was less than expected: 157 patients were directed to the amniocentesis web tool and 36 patients were directed to the breast cancer tool (data were only available from four of the seven breast clinics) (Table 2). Data about the number of patients directed to the PSA website from primary care were not available.

Table 2 also describes considerable variation between clinics in the number of patients who accessed the tool. Three of the antenatal clinics had access rates of 60% or higher; all the other antenatal clinics had access rates of 28% or lower. Having gained access, 26/54 (48%) patients viewed the amniocentesis site for 30 minutes or more, indicating significant levels of interest after overcoming the access hurdle. These data suggest that high proportion of patients will potentially access and use decision support tools: how best to motivate professionals to direct patients to these interventions is a challenge.

Interviews with health professionals: During phases 1 and 2, 57 interviews were conducted with health care professionals, across all sites, (see Table 3). Interviews in phase 2 focused on examining reasons for the unexpected low number of patients directed to use the decision support tools and what steps might be helpful in embedding patient decision support into routine practice. Analysis of the interviews revealed overall resistance to directing patients to use decision support. This resistance arose from existing professional attitudes and to barriers arising from current organisational routines. Box 1 illustrates the main themes found in the data:

Box 1 Summary of themes derived from the qualitative analysis

Theme	Summary
1. Limited motivation to use patient decision support	Low motivation for the intended role of patient decision was encountered, as illustrated by uncertain deployment of the tools in clinical pathways and low uptake by patients
2. 'We already do shared decision making'	Strong perception that clinicians were already involving patients in decisions, therefore no perceived need to change or to adopt decision support by adapting pathways
3. Perceived patients' barriers to	Clinicians cited barriers such as technical access problems

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involvement in decision making	and often saw patients as those that did not want to be involved in shared decision making or as those they felt had already accessed information on the internet
4. Organisational resistance to patient's involvement in decision making	External efficiency targets and health professionals' views about effective treatments were barriers

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Theme 1 Limited motivation to use patient decision support

The majority of key professionals, specialists, nurses and managers, had been invited to brief introductions about the websites and had been sent an information pack. However, interviews revealed that many clinicians had not fully understood the intended role of the tools~~, often ascribed to difficulty attending key meetings~~. ~~Delays in the launch of the tools meant that professionals had not seen the websites, and were therefore uncertain about the content and also where exactly to position them in their clinical pathways.~~

Ideally, decision support tools should be used by patients when diagnosis and treatment options are confirmed. In urology, this is after urine flow dynamics or biopsies have provided a diagnosis; in knee clinics, this is after osteoarthritis has been confirmed as the likely cause of pain. However, many clinicians saw these tools as merely means for providing information and not as ways of engaging patients in discussions about treatment ~~discussions~~decisions. ~~, provided they did not disrupt clinical workflows.~~ Clinicians reported being happy with: "*… anything that makes the patient genuinely more knowledgeable …" (*orthopaedic surgeon, site 3, phase 1). However, ~~) but~~ the concept that patients should use these tools to engage in decisions was not widely understood: *"Having a summary sheet is fine for the patient but don't expect me to use it … it would interfere with what I do, although I can see it might lead to less questions – which is good"* (orthopaedic surgeon, site 2, phase 1).

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Theme 2 'We already do shared decision making'

The interviews revealed a widely held belief that decisions were already shared with patients and that this was occurring without the need for patient decision support. As one nurse commented, *"I don't know how much more they could be involved [in decisions]"* (antenatal screening nurse, clinic 7). An antenatal specialist stated that: *"… we moved away from the patriarchal ideal of telling people what to do 20 years ago"* (specialist, clinic 7). Many clinicians espoused the view that: *"… you wouldn't replace the time you spend with patients by giving them a decision tool … and the shared decision making process … isn't dependent on having this kind of tool"* (breast care nurse, clinic 4).

Theme 3 Perceived patient barriers to involvement in decision making

Patients' inability to access the Internet was often raised. *"You wonder if they've got access, especially to broadband ..."* (specialist nurse, site 4, phase 1) and that: *"This generation are not used to getting information in this way"* (specialist nurse, site 6, phase 1). Clinicians also gave examples of patients resisting involvement in decisions. A surgeon reported one woman saying, *"I'll do whatever you say. You tell me to have a mastectomy, I'll have a mastectomy …"* (breast surgeon, clinic 4). A breast care nurse commented, *"... most women… say 'you make the decision for me … it's much easier if you tell me what I have to have done'"* (breast care nurse, clinic 4). Patients were often categorised as either "sufficiently informed" or misinformed, "*clutching internet printouts*" (breast surgeon, clinic 3). The prevailing view among interviewees was to accept, that, *"there is a role for your website but that cohort is very narrow ..."* (breast surgeon, clinic 1).

Theme 4 Organisational resistance to patient's involvement in decision making

External targets were often cited as barriers. Meeting efficiency targets, particularly in cancer, led to constant pressures. As a specialist explained, the constant pressure to *"get to a decision*" quickly means that clinicians do not *"… want to encourage indecisive patients go off* [to read a web tool]*, and then … come back and see us for another consultation"* (breast surgeon, clinic 1).

Many clinicians were explicit that they would not direct patients to tools that do not support their own views about effective treatments. For example, the breast cancer tool lists mastectomy and breast conservation surgery as treatments that should both be given consideration by women who have early breast cancer. Yet, many clinics have a different ethos. As one surgeon stated: *"We obviously try to do breast conservation whenever we can. That's the basic premise…"* (breast surgeon, clinic 1). This attitude is supported by external audits, where high mastectomy rates are viewed as inappropriate.

Routines were perceived as already being under pressure and so asking *"... a midwife to give [information about a web tool] was yet another thing …"* (antenatal screening coordinator, clinic 1). Existing processes were viewed as being satisfactory*: "I would say that what we're doing is actually fine"* (screening midwife, clinic 4) and that the website's *"information does not make women's decision about amniocentesis any easier"* (specialist, clinic 7). In short, it was felt that sufficient information was already available: most clinics did not see the websites as adding value to their work, and therefore saw no need for change. Nevertheless, three antenatal clinics achieved relatively high uptake rates, more importantly perhaps, access rates of 60% or higher (clinics 1, 6 and 7 – see Table 2). Interviews revealed that these three clinics had specifically modified their pathways and were alerting women by telephone about the tool at the same time as giving them their 'high risk' result and offer of amniocentesis. Women at clinic 7 were encouraged to access the website before attending their amniocentesis counselling session. Where the tools are integrated into routines, and expectations set that patients will use them before making decisions, different patterns of use emerge.

~~*Patient interviews and survey*~~

~~Ten patients in phase 1 volunteered for telephone interview (Table 3). These patients were positive about the balanced information about treatment options and were satisfied with the clarity of the website. Technical problems were confirmed. Patients also reported unmet expectations – that having become informed, it was disappointing to meet clinicians who were unwilling to involve them in decision making. In phase 1, 45 patients responded to the survey: 84% were very positive about the usefulness of the site, and 85% very positive about the ease of use, 76% were more positive about their upcoming outpatient appointment and 69% said that viewing had made a difference to their decision about treatment. In open comments, patients emphasised the advantage of being recommended high quality information that was available when it suited them, as one respondent said: "…*in my own time, in my own space and at my own pace*". No volunteers for interviews or responses to surveys were received in phase 2.~~

Discussion

Principal Findings: This evaluation demonstrates that the implementation of patient decision support into routine practice is unlikely to be accomplished by the development of web-based tools alone: the relatively low uptake of the tools was explained by clinicians' uncertainty about the content and also where exactly to position them in their clinical pathways, their perception that 'shared decision making' was already commonplace in their teams. A minority also felt that patients, on the whole, are resistant to engaging in decisions. In addition, there was evidence that external factors, such as efficiency targets and 'best practice' recommendations, are viewed as have more influence in driving decisions than the informed preferences of patients.

In short, clinicians did not feel the need to direct patients to use decision support tools, web-based or not, and, as a result, felt no requirement to change existing routines. Taken together, these views represent significant barriers and explain why, in most of the clinics, few patients were directed to use the tools.

It was encouraging however to notice that the data revealed that many patients, when directed to these tools, are willing to use them.~~ and find them helpful. ~~Uptake is highest when clinicians set expectations that these tools are integral to practice and embed their use into clinical pathways.

Strengths and weakness of methods: The strengths of the study are the pragmatic use of routine NHS settings, the purposive sampling of those who had been actually tasked to introduce patients to these web-based decision support tools. The ~~and the~~ use of web server logs to track access ~~– so that~~provides direct data about the actual use of the tools ~~could be tracked~~. Constraints were placed on the intensity of the evaluation processes by the tight service delivery timetables ~~imposed~~ set by the NHS sponsor.

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Although relevant clinicians were interviewed in all sites, the sample could have been expanded if more time had been available.~~ A weakness of the study is the lack of patient interviews in the second evaluation phase, attributable to low uptake of the tools .~~ Although the study sheds some light on some the implementation barriers, further work is needed into understand how to identify patients that would benefit from being asked to use decision support, i.e. to determine the eligible numbers in any given clinical pathway as a way of establishing the denominator population for assessing uptake.

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Results in context of other similar work: Previous work on web-based patient decision support interventions has been typically undertaken in the context of randomised trials (1) and so it is difficult to draw comparisons to this pragmatic implementation study. Nevertheless, existing research studies do illustrate high degrees of difficulty in recruiting patients to use web-based interventions, even with dedicated resources and incentives (10)(11)(12). Holmes Rovner documented a decade ago that engaging clinicians to direct patients to use decision support tools active participants was a significant barrier to implementation (13). Caldon also documented of the concerns and anxieties of health professionals about patient decision support, such as the threat to clinical autonomy, the fear of more demanding patients and suspicion that the content was did not accord with their personal practice (4). These findings are echoed by recent reviews (14)(6)(15).

*Implications***:** As recently noted by Coulter (7), addressing the implementation challenge will require efforts targeted at changing hearts, minds and systems. More preparation and training might be helpful but future work will also need to work on achieving organisation-wide agreement about the role of these interventions and their location in clinical pathways.

Funding and Ethical Approval: NHS Direct were commissioned by the East of England Strategic Health Authority to adapt, host and evaluate the use of patient decision support in England. NHS Direct provided funding for the evaluation, considered the evaluation under their research governance process and given the service evaluation nature of the study, decided that ethical approval was not required. NHS Direct had no involvement in the drafting of this article.

Acknowledgements: We acknowledge the support and advice of the following people. Marie Anne Durand, at the time Programme Manager of the UK SDM Programme, Steven Laitner, SDM Programme Lead, Nick Chapman, Chief Executive Officer NHS Direct and Shirley Large, Head of Research NHS Direct.

Contributorship: GE and AR designed the evaluation; AR and DJ undertook the interviews and conducted the qualitative analysis. TH undertook the quantitative analysis of the web log data. GE drafted the manuscript and is the guarantor and all authors contributed to the writing and editing process.

Data sharing: There is no additional data available.

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Why clinicians don't refer patents to online decision support tools: interviews with front line providers in the NHS.

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Why clinicians don’t refer patents to online decision support tools? Interviews with front line clinics in the NHS.

Glyn Elwyn, Andrew Rix, Tom Holt, Deborah Jones

Cochrane Institute of Primary Care and Public Health
Neuadd Meirionydd
School of Medicine
Cardiff University
Heath Park
United Kingdom
CF14 4YS

Glyn Elwyn, professor, elwyng@cardiff.ac.uk
Andrew Rix, independent researcher, andrewrixhome@gmail.com
Tom Holt, independent researcher, tbholt1@gmail.com
Deborah Jones, independent researcher, deb.jns64@gmail.com

Address for correspondence: Glyn Elwyn - glynelwyn@gmail.com

Keywords: patient decision support, decision aids, shared decision making, patient centred care, informed consent.

All authors have completed the Unified Competing Interest form http://www.icmje.org/coi_disclosure.pdf (available on request from the corresponding author) and declare: no support from any organisation for the submitted work [or describe if any]; no financial relationships with any organisations that might have an interest in the submitted work in the previous three years [or describe if any], no other relationships or activities that could appear to have influenced the submitted work [or describe if any].

Summary

Focus

- Research studies demonstrate that engaging patients in the use of decision support (decision aids) is beneficial but there are significant challenges to their implementation into practice
- Clinicians are in a position to advocate the use of patient decision support but do not appear to do so.

Key messages

- Reluctance to refer patients to decision support is largely based on the scepticism of professionals that these tools add value, coupled with difficulties of incorporating the tools into existing workflows and competing organisational pressures, such as targets
- This reluctance will not be overcome simply by placing tools on the web
- When appropriately directed, a significant number of patients do use the decision support and say they find them useful.

Strengths and Limitations

- The evaluation study upon which these results are based set out to explore patterns of usage but turned to examine why take up was lower than expected
- The evidence comes mainly from 57 qualitative interviews with healthcare professionals taking part in the introduction of six web-based decision support tools hosted on the NHS Direct website

Abstract

Objective: To assess whether clinical teams would direct patients to use web-based patient decision support interventions (DESIs) and whether patients would use them.

Design: Retrospective semi-structured interviews and web server log analysis.

Participants and settings: 57 NHS professionals (nurses, doctors and others) in orthopaedic, antenatal, breast, urology clinics and in primary care practices across 22 NHS sites given access to DESIs hosted on the NHS Direct web-site.

Results: Fewer than expected patients were directed to use the web tools. The most significant obstacles to referral to the tools were the attitudes of clinicians and clinical teams Technical problems contributed to the problems but the low uptake was mainly explained by clinicians' limited understanding of how patient DESIs could be helpful in clinical pathways, their perception that 'shared decision making' was already commonplace and that, in their view, some patients are resistant to being involved in treatment decisions. External factors, such as efficiency targets and 'best practice' recommendations were also cited being significant barriers. Clinicians did not feel the need to refer patients to use decision support tools, web-based or not, and, as a result, felt no requirement to change existing practice routines. Uptake is highest when clinicians set expectations that these tools are integral to practice and embed their use into clinical pathways.

Conclusions: Existing evidence of patient benefit and the free availability of patient DESIs via the web are not sufficient drivers to achieve routine use. Health professionals were not motivated to refer patients to these interventions. Clinicians will not use these interventions simply because they are made available, despite good evidence of benefit to patients. These attitudes are deep seated and will not be modified by solely developing web-based interventions: a broader strategy will be required to embed DESIs into routine practice.

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Introduction

Are clinical teams willing to ask patients to use decision support interventions, when hosted on the web? A decade of research has demonstrated consistent positive outcomes when patient decision support interventions, often called decision aids, are evaluated in randomised controlled trials (1). Use of these interventions is advocated in order to help achieve shared decision making – where patients and clinicians work together to arrive at decisions that best match the informed patient preference (2). These interventions typically consider clinical situations where there are reasonable alternatives. Typical examples are whether to proceed to a total knee replacement or use alternative treatments or whether to accept or decline an amniocentesis, a procedure that runs the risk of leading to a miscarriage. When these interventions are used, patient knowledge increases, risk perceptions are more accurate, patients feel more actively involved in decisions and often tend to make more conservative choices, especially when considering discretionary surgery (1).

Despite good evidence and increasing policy support, studies have revealed resistance to the implementation of shared decision making and decision support (3). Professionals often hold the view that they 'already do' shared decision making, that the interventions promoted lack applicability to individual patients and that there is insufficient time to involve patients in decisions (4). To date, only a few studies have addressed the use of implementing these interventions in routine clinical settings (5). Many obstacles have been described and it is too early to say whether the benefits observed in randomised trials can be replicated (6). As yet, there has been no large scale study to assess the uptake possible in pragmatic settings (7).

Responding to the potential benefits of shared decision making and the use of patient decision support, the NHS in England invested approximately £1.5M in 2009-10 creating a platform of web-based patient decision support, as part of an England-wide shared decision making programme. NHS Direct was commissioned by the East of England Strategic Health Authority to adapt, host and pilot the introduction of web-based decision support interventions into the NHS, as part of the Quality Innovation, Performance and Prevention Programme.

A multi-phase programme of work was proposed, with the aim of creating an easily accessed web-based set of patient decision support tools hosted on an NHS web-platform coupled with telephone support (2). An external evaluation was set up to assess whether clinical teams would direct patients to these tools and to assess uptake and use. This article reports on the attitudes of participating staff which lie behind the reluctance to refer patients to these tools.

Methods

Two phases were planned. In each phase, three web interventions were adapted and hosted on NHS Direct's website. NHS sites were recruited into evaluation pilots of approximately three-month's duration – see Table 1.

In phase 1, the three interventions were adaptations of programmes originally developed by the Foundation for Informed Decision Making, Boston (see Table 1). The prostate web interventions were originally produced in DVD versions and had been previously introduced into some clinics in England (8)(9).

Eight NHS clinics, across England, some with previous involvement in the development of the DVD and web-based versions, agreed to introduce patients to them. For the knee condition, patients referred to secondary care were identified by staff and directed to access the web-based tools to read information about a range of treatment options, e.g. physiotherapy, injections and knee replacement. If patients completed the use of the web tool, a personalised summary was generated that listed their preferred treatment. Patients were asked to either print this summary or, when they attended their next clinic appointment, to ask for the summary to be discussed with them. It had been estimated that 360 patients across three clinics would be eligible to use the knee osteoarthritis web intervention during the evaluation period. Similar methods were applied to the web tools for BHP and LPC.

In phase 2, three interventions were adapted from tools developed at Cardiff University (Table 1). Data was collected from 7 breast cancer and 7 antenatal outpatient clinics recruited by NHS Direct (Table 2). Estimates of patients potentially eligible for these tools had been set at 50 per site, a pool of around 700 patients. Primary Care Trusts in England were asked to contact primary care practices, alerting clinicians to the availability of the PSA decision support tool.

Data Collection

Data was collected in each phase for a maximum of 14 weeks using the following methods:

Referral data: In both phases, clinics kept a record of patients directed to use the tools. Patients were given unique access codes, enabling anonymised tracking of server web logs.

Web logs: web server log data was collected, tracking access (content and duration) of each web page viewed.

Interviews with health professionals: After informed consent was obtained, semi-structured interviews were conducted with medical and nursing specialists responsible for implementing the intervention at each clinic. The respondents were asked their views about the web-based patient decision support and whether they had referred patients to them, we asked about the role they might play in their work. Interviews were conducted at the start, mid-point and end of the pilots, audio-recorded and transcribed. Results from the evaluation of the first phase led to a change of focus for the evaluation of the second phase.

Data analysis: Web server log data were verified, cleaned and analysed by TH. AR and DJ coded the interviews independently, meeting to agree coding frames, prior to jointly categorising the data into themes related to clinician views about the decision support tools and their willingness to direct patients to them.

Results

Patient's access and use: Records indicate that 162 of the estimated potential pool of 360 patients were offered access to the OA knee tool: 102 of the 162 visited (63%) visited the site, at least briefly. A total of 38 (23%) provided some information; 27 patients (26%) used the site in sufficiently to produce a summary sheet that could be used in a future clinic appointment. This number represents 7% of those estimated to have been eligible. No estimates were available for eligible patients in relation to BPH and LPC, or for numbers directed to the sites. Web log data showed 24 and 8 unique visitors to the LPC and BPH sites respectively, resulting in 5 and 2 patients using the sites from introductory pages to summary page, answering all questions.

To compensate for the unexpected access rates in phase one, the number of participating clinics planned for phase two was increased. Based on attendance rates, 700 patients had been considered eligible (50 at each of 14 clinics). The actual uptake was less than expected: 157 patients were directed to the amniocentesis web tool and 36 patients were directed to the breast cancer tool (data were only available from four of the seven breast clinics) (Table 2). Data about the number of patients directed to the PSA website from primary care were not available.

Table 2 also describes considerable variation between clinics in the number of patients who accessed the tool. Three of the antenatal clinics had access rates of 60% or higher; all the other antenatal clinics had access rates of 28% or lower. Having gained access, 26/54 (48%) patients viewed the amniocentesis site for 30 minutes or more, indicating significant levels of interest after overcoming the access hurdle. These data suggest that high proportion of patients will potentially access and use decision support tools: how best to motivate professionals to direct patients to these interventions is a challenge.

Interviews with health professionals: During phases 1 and 2, 57 interviews were conducted with health care professionals, across all sites, (see Table 3). Interviews in phase 2 focused on examining reasons for the unexpected low number of patients directed to use the decision support tools and what steps might be helpful in embedding patient decision support into routine practice. Analysis of the interviews revealed overall resistance to directing patients to use decision support. This resistance arose from existing professional attitudes and to barriers arising from current organisational routines. Box 1 illustrates the main themes found in the data:

Box 1 Summary of themes derived from the qualitative analysis

Theme	**Summary**
1. Limited motivation to use tools designed to support patients participate in decisions	Low motivation for the intended role of patient decision was encountered, as illustrated by uncertain deployment of the tools in clinical pathways and low uptake by patients
2. 'We already do shared decision making'	Strong perception that clinicians were already involving patients in decisions, therefore no perceived need to change or to adopt decision support by adapting pathways
3. Perceived patients' barriers to involvement in decision making	Clinicians cited barriers such as technical access problems and often saw patients as those that did not want to be involved in shared decision making or as those they felt had already accessed information on the internet
4. Organisational factors that reduce professionals' motivation to involve patients in decision making	External efficiency targets and health professionals' views about the imperative of using *effective* treatments were significant barriers to introducing patient decision support tools

Theme 1 Limited motivation to use tools designed to support patients participate in decisions

The majority of key professionals, specialists, nurses and managers, had been invited to brief introductions about the websites and had been sent an information pack. However, interviews revealed that many clinicians had not fully understood the intended role of the tools. Ideally, decision support tools should be used by patients when diagnosis and treatment options are confirmed. In urology, this is after urine flow dynamics or biopsies have provided a diagnosis; in knee clinics, this is after osteoarthritis has been confirmed as the likely cause of pain. However, many clinicians saw these tools as merely means for providing information and not as ways of engaging patients in discussions about treatment decisions. Clinicians reported being happy with: "*… anything that makes the patient genuinely more knowledgeable …" (*orthopaedic surgeon, site 3, phase 1*).* However, the concept that patients should use these tools to engage in decisions was not widely understood: *"Having a summary sheet is fine for the patient but don't expect me to use it … it would interfere with what I do, although I can see it might lead to less questions – which is good"* (orthopaedic surgeon, site 2, phase 1).

Theme 2 'We already do shared decision making'

The interviews revealed a widely held belief that decisions were already shared with patients and that this was occurring without the need for patient decision support. As one nurse commented*, "I don't know how much more they could be involved [in decisions]"* (antenatal screening nurse, clinic 7). An antenatal specialist stated that: *"… we moved away from the patriarchal ideal of telling people what to do 20 years ago"* (specialist, clinic 7). Many clinicians espoused the view that: *"... you wouldn't replace the time you spend with patients by giving them a decision tool … and the shared decision making process … isn't dependent on having this kind of tool"* (breast care nurse, clinic 4).

Theme 3 Perceived patient barriers to involvement in decision making

Patients' inability to access the Internet was often raised. *"You wonder if they've got access, especially to broadband ..."* (specialist nurse, site 4, phase 1) and that: *"This generation are not used to getting information in this way"* (specialist nurse, site 6, phase 1). Clinicians also gave examples of patients resisting involvement in decisions. A surgeon reported one woman saying, *"I'll do whatever you say. You tell me to have a mastectomy, I'll have a mastectomy …"* (breast surgeon, clinic 4). A breast care nurse commented, *"... most women… say 'you make the decision for me … it's much easier if you tell me what I have to have done'"* (breast care nurse, clinic 4). Patients were often categorised as either "sufficiently informed" or misinformed, "*clutching internet printouts*" (breast surgeon, clinic 3). The prevailing view among interviewees was to accept, that, *"there is a role for your website but that cohort is very narrow ..."* (breast surgeon, clinic 1).

Theme 4 Organisational factors that reduce professionals' motivation to involve patients in decision making

External targets were often cited as barriers. Meeting efficiency targets, particularly in cancer, led to constant pressures. As a specialist explained, the constant pressure to *"get to a decision*" quickly means that clinicians do not *"… want to encourage indecisive patients go off* [to read a web tool]*, and then … come back and see us for another consultation"* (breast surgeon, clinic 1).

Many clinicians were explicit that they would not direct patients to tools that do not support their own views about effective treatments. For example, the breast cancer tool lists mastectomy and breast conservation surgery as treatments that should both be given consideration by women who have early breast cancer. Yet, many clinics have a different ethos. As one surgeon stated: *“We obviously try to do breast conservation whenever we can. That’s the basic premise…”* (breast surgeon, clinic 1). This attitude is supported by external audits, where high mastectomy rates are viewed as inappropriate.

Routines were perceived as already being under pressure and so asking *“... a midwife to give [information about a web tool] was yet another thing …”* (antenatal screening coordinator, clinic 1). Existing processes were viewed as being satisfactory*: “I would say that what we’re doing is actually fine”* (screening midwife, clinic 4) and that the website’s *“information does not make women’s decision about amniocentesis any easier”* (specialist, clinic 7). In short, it was felt that sufficient information was already available: most clinics did not see the websites as adding value to their work, and therefore saw no need for change. Nevertheless, three antenatal clinics achieved relatively high uptake rates, more importantly perhaps, access rates of 60% or higher (clinics 1, 6 and 7 – see Table 2). Interviews revealed that these three clinics had specifically modified their pathways and were alerting women by telephone about the tool at the same time as giving them their ‘high risk’ result and offer of amniocentesis. Women at clinic 7 were encouraged to access the website before attending their amniocentesis counselling session. Where the tools are integrated into routines, and expectations set that patients will use them before making decisions, different patterns of use emerge.

Discussion

Principal Findings: This evaluation demonstrates that the implementation of patient decision support into routine practice is unlikely to be accomplished by the development of web-based tools alone: the relatively low uptake of the tools was explained by clinicians’ uncertainty about the content and also where exactly to position them in their clinical pathways, their perception that ‘shared decision making’ was already commonplace in their teams. A minority also felt that patients, on the whole, are resistant to engaging in decisions. In addition, there was evidence that external factors, such as efficiency targets and ‘best practice’ recommendations, are viewed as have more influence in driving decisions than the informed preferences of patients.

In short, clinicians did not feel the need to direct patients to use decision support tools, web-based or not, and, as a result, felt no requirement to change existing routines. Taken together, these views represent significant barriers and explain why, in most of the clinics, few patients were directed to use the tools.

It was encouraging however to notice that the data revealed that many patients, when directed to these tools, are willing to use them. Uptake is highest when clinicians set expectations that these tools are integral to practice and embed their use into clinical pathways.

Strengths and weakness of methods: The strengths of the study are the pragmatic use of routine NHS settings, the purposive sampling of those who had been actually tasked to introduce patients to these web-based decision support tools. The use of web server logs to track access provides direct data about the actual use of the tools. Constraints were placed on the intensity of the evaluation processes by the tight service delivery timetables set by the NHS sponsor.

Although relevant clinicians were interviewed in all sites, the sample could have been expanded if more time had been available. Although the study sheds some light on some the implementation barriers, further work is needed into understand how to identify patients that would benefit from being asked to use decision support, i.e. to determine the eligible numbers in any given clinical pathway as a way of establishing the denominator population for assessing uptake.

Results in context of other similar work: Previous work on web-based patient decision support interventions has been typically undertaken in the context of randomised trials (1) and so it is difficult to draw comparisons to this pragmatic implementation study. Nevertheless, existing research studies do illustrate high degrees of difficulty in recruiting patients to use web-based interventions, even with dedicated resources and incentives (10)(11)(12). Holmes Rovner documented a decade ago that engaging clinicians to direct patients to use decision support tools active participants was a significant barrier to implementation (13). Caldon also documented of the concerns and anxieties of health professionals about patient decision support, such as the threat to clinical autonomy, the fear of more demanding patients and suspicion that the content was did not accord with their personal practice (4). These findings are echoed by recent reviews (14)(6)(15).

*Implications***:** As recently noted by Coulter (7), addressing the implementation challenge will require efforts targeted at changing hearts, minds and systems. More preparation and training might be helpful but future work will also need to work on achieving organisation-wide agreement about the role of these interventions and their location in clinical pathways.

Funding and Ethical Approval: NHS Direct were commissioned by the East of England Strategic Health Authority to adapt, host and evaluate the use of patient decision support in England. NHS Direct provided funding for the evaluation, considered the evaluation under their research governance process and given the service evaluation nature of the study, decided that ethical approval was not required. NHS Direct had no involvement in the drafting of this article.

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Contributorship: GE and AR designed the evaluation; AR and DJ undertook the interviews and conducted the qualitative analysis. TH undertook the quantitative analysis of the web log data. GE drafted the manuscript and is the guarantor and all authors contributed to the writing and editing process.

Data sharing: There is no additional data available.

Competing Interests: There are no competing interests.

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Table 1 Web-based patient decision support hosted on NHS Direct

Phase 1	**Reasonable options considered**	**Evaluation Period**
Osteoarthritis (OA) of the knee (Sites 1, 2 and 3)	Pain management, lifestyle change, manual therapy, joint injections, knee replacement	June – August 2010
Benign Prostatic Hyperplasia (BPH) (sites 4,5,6,7,8)	Active monitoring, surgical approaches, medication	
Localised Prostate Cancer (LPC) (sites 4,5,6,7,8)	Active monitoring, surgical approaches, medication	
Phase 2		
Amniocentesis (based on AmnioDex) (16)	No test, amniocentesis, chorionic villus sampling	February – April 2011
Breast Cancer (based on BresDex) (17)	Breast conservation surgery (lumpectomy) or mastectomy	
Test for prostate specific antigen (PSA) (based on ProsDex) (12)	No test, PSA test	

Table 2 Patients use of the web-tools during phases 1 and 2

	Number of patients directed	Number of patients accessing	Number using web tool for > 30 minutes
Clinics in Phase 1 §			
Osteoarthritis (OA) of the knee, (Sites 1, 2 and 3)	162	102 (63%)	26 (16%)
Urology: Benign Prostatic Hyperplasia (sites 4,5,6,7,8)	Not known	8	2
Urology: Localised Prostate Cancer (sites 4,5,6,7,8)	Not known	24	5
Clinics in Phase 2			
1 Amniocentesis	32	20 (63%)	11 (55%)
2 Amniocentesis	25	3 (12%)	1 (33%)
3 Amniocentesis	25	3 (12%)	1 (33%)
4 Amniocentesis	32	9 (28%)	4 (44%)
5 Amniocentesis	20	3 (15%)	1 (33%)
6 Amniocentesis	10	6 (60%)	3 (50%)
7 Amniocentesis	13	10 (77%)	5 (50%)
All antenatal clinics	**157**	**54/157 (34%)**	**26/54 (48%)**
1 Breast cancer	12	1 (8%)	1 (100%)
2 Breast cancer	20	0 (0%)	Not applicable
3 Breast cancer	2	0 (0%)	Not applicable
4 Breast cancer	2	0 (0%)	Not applicable
5 Breast cancer	Unknown	2	2 (100%)
6 Breast cancer	Unknown	0	Not applicable
7 Breast cancer	Unknown	1	0 (0%)
All breast cancer clinics	**36**	**4/36 (11%)**	**3/4 (75%)**

§ In phase 1, numbers are aggregated.

Table 3 **Interviews undertaken for each intervention**

	Number healthcare professionals interviewed
Intervention	
Osteoarthritis of the knee	6
Benign Prostatic Hyperplasia	4
Localised Prostate Cancer	5
Amniocentesis	19
Breast Cancer	23
Prostate Specific Antigen	0
Total	**57**

Why ~~don't NHS healthcare professionals~~clinicians don't refer ~~recommend~~ patents ~~use~~ to online~~web-based~~ decision support tools? Interviews from ~~the~~ front line clinics in the NHS~~front line~~.

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Glyn Elwyn, Andrew Rix, Tom Holt, Deborah Jones

Cochrane Institute of Primary Care and Public Health
Neuadd Meirionydd
School of Medicine
Cardiff University
Heath Park
United Kingdom
CF14 4YS

Glyn Elwyn, professor, elwyng@cardiff.ac.uk
Andrew Rix, independent researcher, andrewrixhome@gmail.com
Tom Holt, independent researcher, tbholt1@gmail.com
Deborah Jones, independent researcher, deb.jns64@gmail.com

Address for correspondence: Glyn Elwyn - glynelwyn@gmail.com

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Summary

Focus

- Research studies demonstrate that engaging patients in the use of decision support (decision aids) is beneficial but there are significant challenges to their implementation into practice~~take up is low~~
- Clinicians are in a position to advocate the use of patient decision support ~~by~~ but do not appear to do so.

Key messages

- Reluctance to ~~point~~ refer patients ~~in the direction of~~to decision support is largely based on the scepticism of~~a complex mixture of~~ professionals that these tools add value, coupled with ~~attitudes,~~ difficulties ~~in~~ of incorporating the tools into existing work ~~patterns~~ flows and competing organisational pressures, such as targets
- This reluctance will not be overcome simply by ~~making~~ placing ~~more~~ tools ~~available and more accessible~~on the web
- When appropriately directed, a significant number of patients do use the decision support and say they find them useful.

Strengths and Limitations

- The evaluation study upon which these results are based set out to explore patterns of usage but turned to examine why take up was lower than expected
- The evidence comes mainly from 57 qualitative interviews with healthcare professionals taking part in the introduction of six web-based decision support tools hosted on the NHS Direct website
- ~~Low take-up reduced the opportunity to obtain evidence from patient users.~~
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Abstract

Objective: To assess whether clinical teams would direct patients to use web-based patient decision support interventions (DESIs) and whether patients would use them.

Design: ~~Mixed methods using concurrent and ~~R~~r~~etrospective semi-structured interviews and ~~,~~ web server log analysis. ~~and surveys.~~

Participants and settings: 57 NHS professionals (nurses, doctors and others) in orthopaedic, antenatal, breast, urology clinics and in primary care practices ~~and 10 patients~~ across 22 NHS sites given access to DESIs hosted on the NHS Direct web-site.

Results: Fewer than expected patients were directed to use the web tools. The most significant obstacles to referral to the tools were the attitudes of clinicians and clinical teams. Technical problems ~~partly~~ contributed to the problems but the low uptake was mainly explained by clinicians' limited understanding of how patient ~~they~~ DESIs ~~should~~ could be helpful ~~be located~~ in clinical pathways, their perception that 'shared decision making' was already commonplace and that, in their view, some patients are resistant to being involved in treatment decisions. External factors, such as efficiency targets and 'best practice' recommendations were also cited ~~as having a significant~~being significant barriers. ~~negative influence on clinicians' decisions to refer.~~ Clinicians did not feel the need to ~~direct~~ refer patients to use decision support tools, web-based or not, and, as a result, felt no requirement to change existing practice routines.. ~~However, the data also showed that many patients, when directed to these tools, were willing to access and use them and found them helpful.~~ Uptake is highest when clinicians set expectations that these tools are integral to practice and embed their use into clinical pathways.

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Conclusions: Existing evidence of patient benefit and the free availability of ~~from a Cochrane review and making~~patient DESIs ~~freely available~~ via the web are not sufficient drivers to ~~guarantee~~ achieve routine use. ~~Changes are needed in attitudes and skills as well as system support to reach organisation-wide agreement about the role of these interventions and their location in clinical pathways.~~Health professionals were not motivated to refer patients to these interventions. Clinicians will not use these interventions simply because they are made available, despite good evidence of benefit to patients. These attitudes are deep seated and will not be modified by solely developing web-based interventions: a broader strategy will be required to embed DESIs into routine practice.

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Introduction

Are clinical teams willing to ask patients to use decision support interventions, when hosted on the web? A decade of research has demonstrated consistent positive outcomes when patient decision support interventions, often called decision aids, are evaluated in randomised controlled trials (1). Use of these interventions is advocated in order to help achieve shared decision making – where patients and clinicians work together to arrive at decisions that best match the informed patient preference (2). These interventions typically consider clinical situations where there are reasonable alternatives. Typical examples are whether to proceed to a total knee replacement or use alternative treatments or whether to accept or decline an amniocentesis, a procedure that runs the risk of leading to a miscarriage. When these interventions are used, patient knowledge increases, risk perceptions are more accurate, patients feel more actively involved in decisions and often tend to make more conservative choices, especially when considering discretionary surgery (1).

Despite good evidence and increasing policy support, studies have revealed resistance to the implementation of shared decision making and decision support (3). Professionals often hold the view that they 'already do' shared decision making, that the interventions promoted lack applicability to individual patients and that there is insufficient time to involve patients in decisions (4). To date, only a few studies have addressed the use of implementing these interventions in routine clinical settings (5). Many obstacles have been described and it is too early to say whether the benefits observed in randomised trials can be replicated (6)~~(Francis Légaré et al., 2010).~~. As yet, there has been no large scale study to assess the uptake possible in pragmatic settings (7).

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Responding to the potential benefits of shared decision making and the use of patient decision support, the NHS in England invested approximately £1.5M in 2009-10 creating a platform of web-based patient decision support, as part of an England-wide shared decision making programme. NHS Direct was commissioned by the East of England Strategic Health Authority to adapt, host and pilot the introduction of web-based decision support interventions into the NHS, as part of the Quality Innovation, Performance and Prevention Programme.

A multi-phase programme of work was proposed, with the aim of creating an easily accessed web-based set of patient decision support tools hosted on an NHS web-platform coupled with telephone support (2). An external evaluation was set up to assess whether clinical teams would direct patients to these tools and to assess uptake and use. This article reports on the attitudes of participating staff which lie behind the reluctance to refer patients to these tools.~~This article reports the main findings of the evaluation, based on web-server logs and interviews with clinical staff.~~

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Methods

Two phases were planned. In each phase, three web interventions were adapted and hosted on NHS Direct's website. NHS sites were recruited into evaluation pilots of approximately three-month's duration – see Table 1.

In phase 1, the three interventions were adaptations of programmes originally developed by the Foundation for Informed Decision Making, Boston (see Table 1). The prostate web interventions were originally produced in DVD versions and had been previously introduced into some clinics in England (8)(9).

Eight NHS clinics, across England, some with previous involvement in the development of the DVD and web-based versions, agreed to introduce patients to them. For the knee condition, patients referred to secondary care were identified by staff ~~at the relevant clinics~~ and directed to access the web-based tools to read information about a range of treatment options, e.g. physiotherapy, injections and knee replacement. If patients completed the use of the web tool, a personalised summary was generated that listed their preferred treatment. Patients were asked to either print this summary or, when they attended their next clinic appointment, to ask for the summary to be discussed with them. It had been estimated that 360 patients across three clinics would be eligible to use the knee osteoarthritis web intervention during the evaluation period. Similar methods were applied to the web tools for BHP and LPC.

In phase 2, three interventions were adapted from tools developed at Cardiff University (~~see~~ Table 1). Data was collected from 7 breast cancer and 7 antenatal outpatient clinics recruited by NHS Direct (Table 2). Estimates of patients potentially eligible for these tools had been set at 50 per site, a pool of around 700 patients. Primary Care Trusts in England were asked to contact primary care practices, alerting clinicians to the availability of the PSA decision support tool.

Data Collection

Data was collected in each phase for a maximum of 14 weeks using the following methods:

Referral data: In both phases, clinics kept a record of patients directed to use the tools. Patients were given unique access codes, enabling anonymised tracking of server web logs.

Web logs: web server log data was collected, tracking access (content and duration) of each web page viewed.

Interviews with health professionals: After informed consent was obtained, semi-structured interviews were conducted with medical and nursing specialists responsible for implementing the intervention at each clinic. The respondents were asked their views about the web-based patient decision support and whether they had referred patients to them, we asked about the the role they might play in their work. Interviews were conducted at the start, mid-point and end of the pilots, audio-recorded and transcribed. Results from the evaluation of the first phase led to a change of focus for the evaluation of the second phase.

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~~*Patient interviews and surveys*: Short survey tools addressed questions about usability and assessed knowledge about the relevant condition. Patients also consented to a semi-structured telephone interview about their experience of using the site.~~

Data analysis: Web server log data were verified, cleaned and analysed by TH. AR and DJ coded the interviews independently, meeting to agree coding frames, prior to jointly categorising the data into themes related to clinician views about the decision support tools and their willingness to direct patients to them.

Results

Patient's access and use: Records indicate that 162 of the estimated potential pool of 360 patients were offered access to the OA knee tool: 102 of the 162 visited (63%) visited the site, at least briefly. A total of 38 (23%) provided some information; 27 patients (26%) used the site in sufficiently to produce a summary sheet that could be used in a future clinic appointment. This number represents 7% of those estimated to have been eligible. No estimates were available for eligible patients in relation to BPH and LPC, or for numbers directed to the sites. Web log data showed 24 and 8 unique visitors to the LPC and BPH sites respectively, resulting in 5 and 2 patients using the sites from introductory pages to summary page, answering all questions.

To compensate for the unexpected access rates in phase one, the number of participating clinics planned for phase two was increased. Based on attendance rates, 700 patients had been considered eligible (50 at each of 14 clinics). The actual uptake was less than expected: 157 patients were directed to the amniocentesis web tool and 36 patients were directed to the breast cancer tool (data were only available from four of the seven breast clinics) (Table 2). Data about the number of patients directed to the PSA website from primary care were not available.

Table 2 also describes considerable variation between clinics in the number of patients who accessed the tool. Three of the antenatal clinics had access rates of 60% or higher; all the other antenatal clinics had access rates of 28% or lower. Having gained access, 26/54 (48%) patients viewed the amniocentesis site for 30 minutes or more, indicating significant levels of interest after overcoming the access hurdle. These data suggest that high proportion of patients will potentially access and use decision support tools: how best to motivate professionals to direct patients to these interventions is a challenge.

Interviews with health professionals: During phases 1 and 2, 57 interviews were conducted with health care professionals, across all sites, (see Table 3). Interviews in phase 2 focused on examining reasons for the unexpected low number of patients directed to use the decision support tools and what steps might be helpful in embedding patient decision support into routine practice. Analysis of the interviews revealed overall resistance to directing patients to use decision support. This resistance arose from existing professional attitudes and to barriers arising from current organisational routines. Box 1 illustrates the main themes found in the data:

Box 1 Summary of themes derived from the qualitative analysis

Theme	Summary
1. Limited motivation to use patient decision support	Low motivation for the intended role of patient decision was encountered, as illustrated by uncertain deployment of the tools in clinical pathways and low uptake by patients
2. 'We already do shared decision making'	Strong perception that clinicians were already involving patients in decisions, therefore no perceived need to change or to adopt decision support by adapting pathways
3. Perceived patients' barriers to	Clinicians cited barriers such as technical access problems

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involvement in decision making	and often saw patients as those that did not want to be involved in shared decision making or as those they felt had already accessed information on the internet
4. Organisational resistance to patient's involvement in decision making	External efficiency targets and health professionals' views about effective treatments were barriers

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Theme 1 Limited motivation to use patient decision support

The majority of key professionals, specialists, nurses and managers, had been invited to brief introductions about the websites and had been sent an information pack. However, interviews revealed that many clinicians had not fully understood the intended role of the tools~~, often ascribed to difficulty attending key meetings~~. ~~Delays in the launch of the tools meant that professionals had not seen the websites, and were therefore uncertain about the content and also where exactly to position them in their clinical pathways.~~

Ideally, decision support tools should be used by patients when diagnosis and treatment options are confirmed. In urology, this is after urine flow dynamics or biopsies have provided a diagnosis; in knee clinics, this is after osteoarthritis has been confirmed as the likely cause of pain. However, many clinicians saw these tools as merely means for providing information and not as ways of engaging patients in discussions about treatment ~~discussions~~decisions. ~~, provided they did not disrupt clinical workflows.~~ Clinicians reported being happy with: "*… anything that makes the patient genuinely more knowledgeable …" (*orthopaedic surgeon, site 3, phase 1). However, ~~) but~~ the concept that patients should use these tools to engage in decisions was not widely understood: *"Having a summary sheet is fine for the patient but don't expect me to use it … it would interfere with what I do, although I can see it might lead to less questions – which is good"* (orthopaedic surgeon, site 2, phase 1).

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Theme 2 'We already do shared decision making'

The interviews revealed a widely held belief that decisions were already shared with patients and that this was occurring without the need for patient decision support. As one nurse commented, *"I don't know how much more they could be involved [in decisions]"* (antenatal screening nurse, clinic 7). An antenatal specialist stated that: *"… we moved away from the patriarchal ideal of telling people what to do 20 years ago"* (specialist, clinic 7). Many clinicians espoused the view that: *"... you wouldn't replace the time you spend with patients by giving them a decision tool … and the shared decision making process … isn't dependent on having this kind of tool"* (breast care nurse, clinic 4).

Theme 3 Perceived patient barriers to involvement in decision making

Patients' inability to access the Internet was often raised. *"You wonder if they've got access, especially to broadband ..."* (specialist nurse, site 4, phase 1) and that: *"This generation are not used to getting information in this way"* (specialist nurse, site 6, phase 1). Clinicians also gave examples of patients resisting involvement in decisions. A surgeon reported one woman saying, *"I'll do whatever you say. You tell me to have a mastectomy, I'll have a mastectomy …"* (breast surgeon, clinic 4). A breast care nurse commented, *"... most women… say 'you make the decision for me … it's much easier if you tell me what I have to have done'"* (breast care nurse, clinic 4). Patients were often categorised as either "sufficiently informed" or misinformed, "*clutching internet printouts*" (breast surgeon, clinic 3). The prevailing view among interviewees was to accept, that, *"there is a role for your website but that cohort is very narrow ..."* (breast surgeon, clinic 1).

Theme 4 Organisational resistance to patient's involvement in decision making

External targets were often cited as barriers. Meeting efficiency targets, particularly in cancer, led to constant pressures. As a specialist explained, the constant pressure to *"get to a decision*" quickly means that clinicians do not *"… want to encourage indecisive patients go off* [to read a web tool*], and then … come back and see us for another consultation"* (breast surgeon, clinic 1).

Many clinicians were explicit that they would not direct patients to tools that do not support their own views about effective treatments. For example, the breast cancer tool lists mastectomy and breast conservation surgery as treatments that should both be given consideration by women who have early breast cancer. Yet, many clinics have a different ethos. As one surgeon stated: *"We obviously try to do breast conservation whenever we can. That's the basic premise…"* (breast surgeon, clinic 1). This attitude is supported by external audits, where high mastectomy rates are viewed as inappropriate.

Routines were perceived as already being under pressure and so asking *"... a midwife to give [information about a web tool] was yet another thing …"* (antenatal screening coordinator, clinic 1). Existing processes were viewed as being satisfactory*:* *"I would say that what we're doing is actually fine"* (screening midwife, clinic 4) and that the website's *"information does not make women's decision about amniocentesis any easier"* (specialist, clinic 7). In short, it was felt that sufficient information was already available: most clinics did not see the websites as adding value to their work, and therefore saw no need for change. Nevertheless, three antenatal clinics achieved relatively high uptake rates, more importantly perhaps, access rates of 60% or higher (clinics 1, 6 and 7 – see Table 2). Interviews revealed that these three clinics had specifically modified their pathways and were alerting women by telephone about the tool at the same time as giving them their 'high risk' result and offer of amniocentesis. Women at clinic 7 were encouraged to access the website before attending their amniocentesis counselling session. Where the tools are integrated into routines, and expectations set that patients will use them before making decisions, different patterns of use emerge.

~~*Patient interviews and survey*~~

~~Ten patients in phase 1 volunteered for telephone interview (Table 3). These patients were positive about the balanced information about treatment options and were satisfied with the clarity of the website. Technical problems were confirmed. Patients also reported unmet expectations – that having become informed, it was disappointing to meet clinicians who were unwilling to involve them in decision making. In phase 1, 45 patients responded to the survey: 84% were very positive about the usefulness of the site, and 85% very positive about the ease of use, 76% were more positive about their upcoming outpatient appointment and 69% said that viewing had made a difference to their decision about treatment. In open comments, patients emphasised the advantage of being recommended high quality information that was available when it suited them, as one respondent said: "…*in my own time, in my own space and at my own pace*". No volunteers for interviews or responses to surveys were received in phase 2.~~

Discussion

Principal Findings: This evaluation demonstrates that the implementation of patient decision support into routine practice is unlikely to be accomplished by the development of web-based tools alone: the relatively low uptake of the tools was explained by clinicians' uncertainty about the content and also where exactly to position them in their clinical pathways, their perception that 'shared decision making' was already commonplace in their teams. A minority also felt that patients, on the whole, are resistant to engaging in decisions. In addition, there was evidence that external factors, such as efficiency targets and 'best practice' recommendations, are viewed as have more influence in driving decisions than the informed preferences of patients.

In short, clinicians did not feel the need to direct patients to use decision support tools, web-based or not, and, as a result, felt no requirement to change existing routines. Taken together, these views represent significant barriers and explain why, in most of the clinics, few patients were directed to use the tools.

It was encouraging however to notice that the data revealed that many patients, when directed to these tools, are willing to use them. ~~and find them helpful.~~ Uptake is highest when clinicians set expectations that these tools are integral to practice and embed their use into clinical pathways.

Strengths and weakness of methods: The strengths of the study are the pragmatic use of routine NHS settings, the purposive sampling of those who had been actually tasked to introduce patients to these web-based decision support tools. The ~~and the~~ use of web server logs to track access ~~– so that~~provides direct data about the actual use of the tools ~~could be tracked~~. Constraints were placed on the intensity of the evaluation processes by the tight service delivery timetables ~~imposed~~ set by the NHS sponsor.

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Although relevant clinicians were interviewed in all sites, the sample could have been expanded if more time had been available. ~~A weakness of the study is the lack of patient interviews in the second evaluation phase, attributable to low uptake of the tools .~~ Although the study sheds some light on some the implementation barriers, further work is needed into understand how to identify patients that would benefit from being asked to use decision support, i.e. to determine the eligible numbers in any given clinical pathway as a way of establishing the denominator population for assessing uptake.

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Results in context of other similar work: Previous work on web-based patient decision support interventions has been typically undertaken in the context of randomised trials (1) and so it is difficult to draw comparisons to this pragmatic implementation study. Nevertheless, existing research studies do illustrate high degrees of difficulty in recruiting patients to use web-based interventions, even with dedicated resources and incentives (10)(11)(12). Holmes Rovner documented a decade ago that engaging clinicians to direct patients to use decision support tools active participants was a significant barrier to implementation (13). Caldon also documented of the concerns and anxieties of health professionals about patient decision support, such as the threat to clinical autonomy, the fear of more demanding patients and suspicion that the content was did not accord with their personal practice (4). These findings are echoed by recent reviews (14)(6)(15).

Implications: As recently noted by Coulter (7), addressing the implementation challenge will require efforts targeted at changing hearts, minds and systems. More preparation and training might be helpful but future work will also need to work on achieving organisation-wide agreement about the role of these interventions and their location in clinical pathways.

Funding and Ethical Approval: NHS Direct were commissioned by the East of England Strategic Health Authority to adapt, host and evaluate the use of patient decision support in England. NHS Direct provided funding for the evaluation, considered the evaluation under their research governance process and given the service evaluation nature of the study, decided that ethical approval was not required. NHS Direct had no involvement in the drafting of this article.

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Contributorship: GE and AR designed the evaluation; AR and DJ undertook the interviews and conducted the qualitative analysis. TH undertook the quantitative analysis of the web log data. GE drafted the manuscript and is the guarantor and all authors contributed to the writing and editing process.

Data sharing: There is no additional data available.

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