NHS

Kidney Care

Giving real choice to renal patients:

Embedding patient decision aids

March 2013

Better Kidney Care for All

Contents

1 Introduction

1.1 Background

The national End Stage Renal Failure (ESRF) Patient Decision Aid was released in early September 2012, and in October that year renal units in England were invited to apply for funding to embed the use of the decision aid into their routine clinical practice. The decision aid is designed to support adult patients who need to make decisions about whether or not to have renal replacement therapy, what type of renal replacement therapy to have and where to have it. The national ESRF PDA is available through the NHS Right Care website http://sdm.rightcare.nhs.uk/. As part of a number of resources designed to facilitate implementation of the PDA, NHS Right Care produced a short film about a patient who has been diagnosed with kidney failure using the PDA, which is available on YouTube: http://www.youtube.com/watch?v=fp-BvMA3Dsg

Forty-nine trusts responded to the Expression of Interest request and NHS Kidney Care commissioned 21 projects to take this work forward and embed the use of the Right Care Patient Decision Aid within their units. The programme aimed to support the project groups to redesign care to enable and involve the use of the decision aid for patients. The project lifespan was challenging for all, and ran between December 2012 and March 2013.

This is a summative report of the ‘end of project’ reports from the embedding the Right Care Patient Decision Aid project teams. It draws together the evidence and learning from the work undertaken by these projects during the four month life of the programme. Within the time frame it has not been possible to evaluate patient outcomes; however results in relation to patient and staff experience, and the process behind undertaking the projects are documented here.

1.2 Context

Shared decision making (SDM) is an approach which seeks to optimise patient involvement in decisions. It acknowledges the need to combine patients’ preferences, values and life experiences with clinical expertise around disease management.

Patient Decision Aids (PDAs) can be used to help the delivery of shared decision making. They are designed to help patients make informed and considered decisions about their treatments, to increase their awareness and understanding of the potential risks and benefits of different choices and the likely outcomes. They are intended to complement the information and advice given by clinicians.

1.3 Baseline Survey

In 2012 an evaluation study was undertaken by NHS Kidney Care prior to the start of the Embedding the Right Care Patient Decision Aid Programme. A survey was carried out in order to obtain a snapshot of the use of and attitudes towards PDAs in the kidney units which are currently being supported by NHS Kidney Care to embed new Established Kidney Disease Patient Decision Aids (PDAs) from Right Care. The survey was completed by 21 out of 24 units. Renal units were asked questions in relation to their current experience of using Patient Decision Aids, identifying where they would use the tool:

- Three units (9.5%) were using the Yorkshire Dialysis Decision Aid (YoDDA)
- 95% of units provided patients with patient information leaflets and written information
- 85% provided patients information DVDs
- 67% provided patients with patient information web addresses
- 14% provided access to online resources
- 14% provided patient education sessions and workshops

These findings suggest that despite wide awareness of PDAs they are not currently used routinely in clinical practice within the kidney units surveyed. Furthermore, all bar one unit agreed or strongly agreed that administering PDAs should become part of routine care and that patients would benefit from access to a PDA; therefore confirming that clinicians believe that PDAs will improve quality of care and be useful, albeit as one part of a larger package of care.

Details and results of the survey can be found at:
http://www.kidneycare.nhs.uk/our_work_programmes/empowering_patients/shared_decision_making/patient_decision_aid/

To support the use of the Right Care Patient Decision Aid there are three Shared Decision Making (SDM) leaflets which can be downloaded via the website. http://sdm.rightcare.nhs.uk/. These are intended for use in consultation and can also be given to patients, to promote and inform discussion and enable shared decision making. They might also prompt referral to the PDA itself.

It is expected that patients who have been identified as needing to make a decision about renal replacement therapy will be referred to the ESRF PDA and will then be offered an opportunity at subsequent appointments to discuss any questions or concerns that have arisen.

Patients are directed to the ESRF PDA by their clinical team, and those who do not routinely use the internet may need support to access the tool. As part of the Expression of Interest renal units were invited to help develop innovative and appropriate ways of engaging diverse patient groups, including those without access to the internet, to enable use of the tool.

Funding was made available for each successful renal unit to help staff embed the use of the ESRF PDA. Project management support was available from NHS Kidney Care and the funding awarded subject to governance arrangements set out in the agreed project profile.

The primary aims of this programme were for units to:

- Allocate time for identified team members to be trained to implement the PDA with kidney patients and to then lead on training other members of the team.
- Engage service users in service redesign to incorporate use of the PDA.
- Explore and implement ways of engaging diverse patient groups with the PDA, including those who do not have home internet access and those who do not have English as a first language.
- Enable staff to come together, both within units and across regions, to share practical experiences and attitudes to use of the PDA and its role in the broader implementation of shared decision making.
- Enable key clinicians to attend Advanced Communication Skills Training. This might include motivational interview techniques.

- Evaluate and report on the experience of using the PDA. Units were required to
    - a) complete an NHS Kidney Care survey about PDAs at the beginning and end of the project
    - b) survey staff and patients about their experience of using of the PDA
    - c) implement any evaluation measure provided centrally by NHS Kidney Care to give consistency across the project sites

1.4 *Overarching success criteria*

The key success criteria for the project teams to work towards were defined as:

- Identify suitable patients and refer at least 80% of them to the PDA and/or use shared decision making sheets with them.
- Explore and implement ways of delivering the PDA to diverse patient groups.
- Demonstrate awareness of and commitment to use the resource amongst wider colleagues.
- Deliver advanced communication skills training for key clinicians.
- Evaluate:
    - The number of patients who have used the PDA/SDM sheets;
    - The number of clinicians using or referring patients to the PDA and/or SDM sheets.
    - Patient and staff experience of using the PDA.
- Share findings and learning with other renal units
- Link their project with other projects aiming to improve choice: http://www.kidneycare.nhs.uk/our_work_programmes/improving_choice_for_kidney_patients/_and empower_patient

Shared learning was an essential component of the project both within and across local kidney care networks, primarily using e-technology such as e-seminars hosted by NHS Kidney Care. NHS Kidney Care also provided access to suitable collaborative learning facilitators and communication trainers where needed.

1.5 *Shared Decision Making*

The involvement of patients in health decision-making is now seen as critical to improving health outcomes. Research shows that involving patients in their own care improves their experience and satisfaction with NHS services, as well as the appropriateness and outcomes of care. For patients to feel involved in their care it is imperative that they are treated as equal partners, listened to, and provided with adequate information. This approach will only be successful when the individuals have good understanding of their condition as well as access to any additional information they need in order to self-manage effectively and participate in any decision making.

Shared decision making is the process of negotiation, discussion and decision making that takes place between the professional and the individual. The process brings together the concepts and principles of patient involvement, shared decision making, self-care support and patient centred care. A review of the literature carried out by NHS Kidney Care in 2011 (http://www.kidneycare.nhs.uk/document.php?o=463) reported a positive correlation between patient participation in decision making and satisfaction with care received. The review also showed that timely and adequate access to information is necessary to help patients make the right decisions and participate effectively in their own care.

1.6 Policy context

Improving the care and quality of life for all people with long term conditions is embedded throughout the NHS Outcomes Framework http://www.dh.gov.uk/health/2012/11/nhs-outcomes-framework/ and the NHS Mandate http://mandate.dh.gov.uk/. The project work was also undertaken against the backdrop of the renal National Service Framework (NSF) standards http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4101902 which require that patients become informed partners in their care, with a personal care plan. This project also relates to the long term conditions work stream of the Quality, Innovation, Productivity and Prevention (QIPP) programme. In addition, the provision of 'a current agreed care plan appropriate to the stage and rate of progression of CKD' is a key goal of the National Institute for Health and Clinical Excellence (NICE) quality standards for chronic kidney disease (CKD) http://guidance.nice.org.uk/QS5 as stated in the third quality statement. For service providers, health and social care professionals, and commissioners, this quality requirement ensures that systems are in place to develop and maintain current agreed care plans with people who have CKD. For people with CKD, it ensures that they receive appropriate information which explains their condition and the care they will receive, and are involved in decisions about their current and future care.

2.0 NHS Kidney Care approach

The NHS Kidney Care approach offers a systematic way to identify needs and set priorities for improving care - at organisation, practice, and patient levels - by supporting locally-led implementation. Central to NHS Kidney Care's approach is the concept that providing patients with timely and adequate information and their participation in decisions about their care can improve patient outcomes. The ultimate goal of the approach is to have informed patients who are active in their care, and providers who have resources and expertise, thereby developing a sustainable positive legacy while achieving better care for patients with kidney disease.

2.1 General support

NHS Kidney Care provided a package of general support to all of the project sites giving them the opportunity to access specialist advice and share experience and knowledge with others. It was intended to ensure the long-lasting impact and success of the initiative. It involved the input of the NHS Kidney Care Fellow and Programme Lead for the Shared Decision Making Projects. The input of the NHS Kidney Care Fellow was particularly beneficial for project teams when their proposals were at an early stage, indicating issues which might require further exploration or mitigation. The NHS Kidney Care monthly reporting system also helped the project teams to document their progress and key learning from implementation.

2.2 Programme support

The programme was launched with a national meeting, open to all applicants. During this meeting attendees were introduced to the PDA, the design, development and operational details. This session workshop was chaired by the programme clinical lead and Right Care representation. Other support included:

2.3 Learning network and forums

NHS Kidney Care created and facilitated a learning network for the project leads which provided opportunities for the project groups to interact with each other to share common concerns and experiences. This group met via regular e-seminars held to monitor progress and facilitate sharing of learning and good practice. This was supported by an on-line learning forum that allowed the sharing of key resources. Project leads acknowledged the value of this support in driving the project forward, avoiding duplication and maximising spread of innovation.

3 The project findings

The following sites received funding to take part in the Embedding the Right Care Patient Decision Aid Programme:

- Addenbrooke’s Hospital
- St George's Healthcare NHS Trust
- Imperial College Healthcare NHS Trust
- Aintree University Hospitals NHS Foundation Trust
- Bart’s Health NHS Trust
- Heart of England NHS Foundation Trust
- Bradford Teaching Hospitals NHS Foundation Trust
- Colchester Hospital University NHS Foundation Trust
- Wirral University Teaching Hospital NHS Foundation Trust
- The Royal Liverpool and Broadgreen University Hospitals NHS Trust
- Brighton and Sussex University Hospitals NHS Trust
- North Bristol NHS Trust
- Plymouth Hospitals NHS Trust
- Newcastle upon Tyne Hospitals NHS Foundation Trust
- Epsom and St Helier University Hospitals NHS Trust.
- Lancashire Teaching Hospitals NHS Foundation Trust
- King's College Hospital NHS Foundation Trust
- Oxford University Hospitals NHS Trust
- Norfolk & Norwich University Hospitals NHS Foundation Trust
- Sheffield Teaching Hospitals NHS Foundation Trust
- Gloucestershire Hospitals NHS Foundation Trust
- Royal Cornwall Hospitals NHS Trust

Prior to the end-March completion date, services were asked to submit an end of project report. For many this will act as an interim picture of progress since usage of the PDA will continue after the life of NHS Kidney Care.

3.1 Overview of project deliverables and team experiences

As part of the project profile, each site signed up to the achievement of a number of project deliverables:

3.1.1 Implementation of project deliverables and evaluation of project experiences

Feedback from sites in relation to allocation of time for identified team members to be trained to implement the PDA with kidney patients and to then lead on training other members of the team:

Central to all projects was a need for there to be a 'train the trainer' approach to up-skilling staff in the use and application of the PDA. All project teams used a cascade approach and, starting with the project team lead who had been through the use of the PDA at the national launch meeting, spread the training throughout the wider team members. Not all of the team training was completed by the time of reporting but all were working towards achieving this on a rolling programme. Training of the wider team had not always been easy to arrange due to the short time frames and availability. However where delays had existed – this did not appear to be reflective of interest in or commitment to the PDA tool.

Wider staff training was managed through a mix of 1:1 sessions, staff education sessions carried out involving the whole MDT explaining the concept of shared decision making, care planning, the PDA tool and through the use of case studies. In many cases training involved multi professional teams – nurses, nurse assistants, dieticians, renal pharmacists, social workers, counsellors and doctors. Attending awareness raising sessions about the PDAs involved being shown how to use the PDAs and use and access in the shared decision making sheets.

Addenbrooke's Hospital took an action learning approach to development, to allow both the core low clearance clinic staff and the wider nephrology team to be involved in development and take ownership of those aspects relating to their area of practice. Staff attended a number of e-seminars and face to face meetings to allow cross-pollination of ideas and practical tips.

In preparation for their discussions with patients, PDA nurses attended brief education programmes some in areas they felt they had less knowledge of e.g. at the The Royal Liverpool and Broadgreen University Hospitals NHS Trust, PDA nurses enhanced their own experiences with sessions in transplantation (assessment of patients referred and seminars) and dedicated conservative management clinics. Nurses from other groups liaised with their counterparts at The Royal Liverpool and Broadgreen University Hospitals NHS Trust in the free exchange of ideas.

All project teams were required to undertake training in the use of the Patient Decision Aid, as well as Advanced Communication Skills Training or Motivational Interviewing. This training was to ensure that staff had the confidence and skills to manage difficult conversations with patients and to encourage patients to engage with decisions about their care.

Ensuring that the key team members were trained posed further challenges for the teams, again as a result of the tight timeframes; some teams found it hard to ensure that all team members were trained by the time of reporting. North Bristol NHS Trust reported that uptake was not as high as anticipated in spite of team members organising sessions and emailing out dates. This poor uptake was echoed across a number of the project sites the majority of which did not complete the planned team training by the end of the March 2013. This was felt to be due to a lack of time to attend. All project teams were committed to the value of Motivational Interviewing or Advanced Communication Skills training so were working hard to ensure that all members had a date to attend. The Royal Liverpool and Broadgreen University Hospitals NHS Trust, Plymouth Hospitals NHS Trust Bradford Teaching Hospitals NHS Foundation Trust sites had reported using clinical psychologists to drive training within the unit and the development of 'in-house' motivational interviewing/advanced communication days as a rolling programme for all key staff members to attend.

Amongst the trusts arranging in-house training, Plymouth Hospitals NHS Trust and King's College Hospital NHS Foundation Trust arranged in-house Motivational Interviewing training, with King's College Hospital NHS Foundation Trust reporting that more than 30 people had attended the first half day training session. The session had had a marked impact with a great deal of discussion about motivational interviewing within the clinical team. The phrase 'give the monkeys back' (used in training to illustrate the importance of allowing patients to keep ownership of their problems and behaviours) has since been used in numerous settings, demonstrating the impact of the session. A further extension of this training is the planned videoing of consultations with one-to-one feedback.

3.1.2 Patient engagement and service redesign to incorporate the use of the PDA

The level of service redesign needed in order to enable the usage of PDA has varied across the teams. For the majority of units the existence of low clearance clinics, pre-dialysis clinics or renal multi-professional clinics has meant that the cohort of suitable patients has been easily identifiable and accessible. However sites did link up with patient organisations in order to ensure access to patient views and to support the dissemination of the Patient Decision Aid implementation within their area.

Bart's Health NHS Trust, Addenbrooke's Hospital and Heart of England NHS Foundation Trust reported the engagement with and support of the local Kidney Patients Association (KPA) to promote the work being done, and to promote 'buy in' from all patient and carers in this new concept. This engagement informed people of use of the PDA by the wider kidney community and provided feedback on proposed changes and the impact of any changes made on the final delivered service. The local KPA was very enthusiastic in their support and developed links to the PDAs from websites and published an article in the newsletter informing its members about both the project and PDAs

Engaging with patients to embed the use of the PDA took a variety of forms. Addenbrooke's Hospital approach was the incorporation of a broader group educational programme, enabling individual and group learning with the PDA or the SDM version of the PDA and teaching/education in the community during home visits to engage as many individuals as possible.

Sites where there has not been a readily identifiable cohort of patients include those in areas of high ethnic diversity (where family and friends have been enlisted to help engagement) and those where low clearance clinics were not in place. Where the clinics were not already in existence, patients who might benefit from using a PDA were being individually followed up by an education nurse or after outpatient clinic appointments.

Where service redesign did take place, there does not appear to have been much patient engagement in the process and this was reported to be due to time constraints. Bart's Health NHS

Trust has plans to involve patients in the role of expert patients and trainers but there has not been time available to develop and implement this. Brighton and Sussex University Hospitals NHS Trust, Bart's Health NHS Trust, King's College Hospital NHS Foundation Trust and Sheffield Teaching Hospitals NHS Foundation Trust were working towards the development of patient champions to promote 'buy in' from all patient & carers in this new concept – Expert Patient Group members were to lead on this part of the work stream. King's College Hospital NHS Foundation Trust reported that time constraints, once funding was agreed, meant that recruitment of a patient as a trust employee was not feasible. Instead the site opted to invite patients to come to one or two afternoon sessions to demonstrate the PDA, and offer training with a view to recruiting patient leaders. These patients would be paid a fixed 'honorarium' to cover their time and expenses.

Addenbrooke's Hospital reported rearranging the mechanism for transfer of patients from nephrology into low clearance. Patients are now individually approached in nephrology clinics and it is at this stage that the first part of the PDA is introduced, alongside discussions about dialysis and plans for future care. Within low clearance clinics, reformatting the appointments template allowed for longer 'new' patient appointments to extend the introduction of the later parts of the PDA and to begin more in-depth discussions of advanced kidney disease and potential treatments.

Existing patients with significant Chronic Kidney Disease in Aintree University Hospitals NHS Foundation Trust who did not have a decision regarding renal replacement were contacted by letter initially and then subsequently by telephone, giving them advice as to how to access the PDA online for support as well as a face to face discussion within the Day Case unit or at home. Outpatient referrals were invited from colleagues, at their discretion. Patients highlighted were those who had declining renal function. The PDA nurse's role was explained to all colleagues and nurses would sit in clinic with consultants with separate access to computers and hard copies of the short and long forms.

A number of units offered the PDA specifically to in-patients who had presented acutely with significant kidney failure or needing renal replacement therapy (unplanned starters). [Brighton and Sussex University Hospitals NHS Trust, Heart of England NHS Foundation Trust, Sheffield Teaching Hospitals NHS Foundation Trust Oxford University Hospitals NHS Trust.]

Aintree University Hospitals NHS Foundation Trust and Brighton and Sussex University hospital NHS trust used the PDA as part of their existing CKD 4 & 5 care pathway.

At the Norfolk & Norwich University Hospitals NHS Foundation Trust, changes to the patient pathway have resulted in the following changes:

- All new patients are met by an educational nurse and all suitable patients are encouraged to work though the PDAs.
- All relevant letter templates, local unit web pages, information meetings with patients, information leaflets refer to the PDAs with information on what they are and how to access them.
- All staff are being made aware of the PDAs and how to use them. Although as time has been given to the CKD Nurse to do this, patients will be introduced to the PDAs by the CKD Nurse if they have not already had access to them.

For patients being treated at Newcastle upon Tyne Hospitals NHS Foundation Trust, the biggest change to occur from the project has been the implementation of the Right Care PDA in to the pre-dialysis education pathway. This was quite an easy change to instigate and verbal feedback from patients has been very positive about the information the PDA provides. Patients report *"liking the lay out of the information and that it was easy to use and understand".* The PDA supports existing information provided by a Pre-dialysis Nurse Specialist.

Plymouth Hospitals NHS Trust undertook a review of the care pathways in order to embed the PDA. Previously decision making with patients had been consultant-led, supported by the Chronic Kidney Disease (CKD) team, with information given in large chunks. It is now the plan for CKD nurses to lead on shared decision making and provide consistent follow-up, information and education in the OPD setting. This change was supported by medical staff. In some sites the PDA link was being embedded into all future patient care plans with the Care Planning nurses then referring patients to PDA nurses.

Heart of England NHS Foundation Trust cascaded the PDAs and the concept of SDM to the users via the West Midlands Patient - Carer forum task force and expanded this forum to include pre-dialysis patients.

Addenbrooke's Hospital reported having fundamentally re-designed the low clearance service incorporating both the wider nephrology team and also the renal ward and dialysis staff across all areas. The PDA in this case is being used to form the basis of teaching/training in all these areas to provide a consistent high quality service with resources and facilities accessible to all. The results of this will be shared within both the postgraduate renal course for nurses and in the local SpR training days.

3.1.3 Barriers to engagement and barriers to accessing hard to reach groups

The Embedding the Right Care Patient Decision Aid project was open to all sites across England. The successful sites are reflective of the wide demographic found in England, with areas of high ethnic diversity, higher than average elderly population, and highly rural or densely populated communities.

These differences have had an impact on some sites when embedding the patient decision aid.

Bart's Health NHS Trust is located in one the most deprived inner city areas of London where shared decision making can and has been difficult to fully implement. The multi-ethnic, socially deprived patient group has complex care needs, and more than 50% do not speak English as a home language.

The clinicians increasingly aim to promote the practice of "no decision about me, without me" and the impression has been that many (often older, often with a lower level of literacy or where English not a first language) of the patients refer back to the clinician for their professional decision rather than working confidently together to make an informed choice about what the best treatment option for them:

> *"A belief of "the consultant knows best" feels commonplace, and embedding SDM within our population is one of the bigger challenges we face, given that our patients have particular challenges with not speaking English, and with literacy, we strongly believe that we need to consider / develop innovative ways of embedding SDM and the PDA tools in to all our practice"*

A large proportion of patients in Bradford are of South Asian origin. Effective delivery of care for these patients demands a consistently high standard of communication between patients, their families and renal unit staff. Communication may be problematic for a number of reasons, including language barriers and an incomplete appreciation of important cultural or religious beliefs. A minority of these patients are able to read or write Urdu. As a result of this, Bradford Teaching Hospitals NHS Foundation Trust has previously produced audio materials to support patient education projects (for example an initiative to improve the management of hyperphosphataemia by distributing patient information audio cassettes with recorded messages in Urdu).

Also in Bradford Teaching Hospitals NHS Foundation Trust, the appointment of a Cultural and Health Information Officer (CHIO) has contributed to formal discussion and explanation of important clinical issues in the patient's first language (typically Urdu or Punjabi), thereby encouraging patients to feel more involved in decisions about their care and to attend appointments for tests and clinic assessments. The main focus of this work has been the provision of support for patients at key transition points of their renal care, such as decision making about renal replacement therapy, conservative care, transplant work-up and treatment withdrawal as part of our end-of-life care pathway. Some non-English speaking patients found the PDA a useful tool to engage their families in their care through the shared experience of sitting together and being told about choices and possibilities available to them as individuals. It enabled them to share their values and fears with the family.

Where the majority of patients were elderly or did not have access to a computer, teams used the online form of the aid; however the printed versions were described by some as lengthy, cumbersome and not user friendly.

Hard to reach groups were not only defined in relation to language, but the ease of wider accessibility of the PDA. For Colchester Hospital University NHS Foundation Trust:

> *"patients that attend our general clinic at the remote costal clinics - it was felt that often we missed the opportunity to engage them in earlier discussions about planned care, mainly due to time constraints. The PDA has the added benefit of being accessible online, opening up the opportunity for patients to engage alone or with their families at a time that is convenient to them, without having to travel a considerable distance at the early stage of their diagnosis"*

A number found that a proportion of patients were excluded from using the PDA at present due to their inability to read English and also a proportion were excluded to their lack of IT abilities. Sites were keen to have access to the PDA in different languages. Although this did not prevent teams from taking steps to ensure equity of access to the tool amongst their wider patient groups, it did slow down the impact they felt they were making. Lancashire Teaching Hospitals NHS Foundation Trust reported that up to 25% of patients in the main catchment area do not speak English and commented that the use of the aid in this situation was not possible. Teams felt that it was very disappointing that provision had not been made for the tool to be made available in other languages.

Due to lack of local funding, sites were unable to translate phonetically the SDM sheets. Most trusts have not been able to put anything in place specifically to help non-English speaking patients. One team found that due to lack of time and lack of funding, they were unable to hold group sessions with non-English speaking patients.

As noted above, where a large proportion of patients were of South Asian origin, communication may be problematic for a number of reasons, including language barriers and an incomplete appreciation of important cultural or religious beliefs. A minority of South Asian patients are able to read or write Urdu. Such patients may be regarded as being part of a ‘difficult to reach’ group.

The lack of IT literacy unsurprisingly had an impact on usage of the tool. Sheffield Teaching Hospitals NHS Foundation Trust reported that only 52% of the patients were able to use the online decision aid because the remaining 48% did not have access to the internet.

It was a similar story in Epsom and St Helier University Hospitals NHS Trust. In the seven weeks in which the project ran in the trust, 23% of patients introduced to the PDA did not have IT access and when interviewed felt they did not want to be “worried with learning something new”.

IT literacy was mentioned as an issue within the majority of project reports.

3.1.4 Opportunities for staff to come together, both within units and across regions, to share practical experience

A key theme throughout the programme was shared learning. Many trusts were actively publishing the work they were doing with the Patient Decision Aid project within their unit and wider trust; for one an article was included in the KPA newsletter on the initiative and information on the introduction of the PDAs in practice, with the hope that, by advertising the involvement with outpatients, patients would feel empowered to ask their clinicians about their treatment options and in doing so getting more involved in decisions about their care.

Bart’s Health NHS Trust introduced a SDM & PDA section into the monthly pre-dialysis education workshops, as a means of informing all new patients of the initiative and helping the team embed the PDA in routine practice.

Plymouth Hospitals NHS Trust redeveloped patient education with information given earlier and including the concept of self-care and health promotion. The patients had a session on their role within an OPD and how to get the most out of it. Both Bart’s Health NHS Trust and North Bristol NHS Trust reported that the ‘ask 3 questions’ approach was promoted and followed up within the OPD. This was then followed up by an open group session where patients were shown the different treatment options by the specialist nurses and discussions held with expert patients. These changes were to be evaluated as part of the project.

4.0 Experiences and attitudes to use of the PDA and its role in the broader implementation of shared decision making

Use of the PDA varied across sites dependent on when the project had started and the approach they were taking. Gloucestershire Hospitals NHS Foundation Trust offered the tool to 78% of their patients, and Heart of England NHS Foundation Trust to 100% of its eligible population. The conclusion that can be drawn here is that project sites were very quickly offering the tool to their eligible population regardless of issues such as poor translation availability.

The evaluation of the tool was restricted by the lifespan of the programme, and all sites remain committed to continuing to capture evaluation data after the life of the NHS Kidney Care, recognising that this is an exciting and innovative piece of work and robust evaluation is central ensuring sustainability of these tools in the future.

Teams were asked to feed back on both patient and staff experience of using the Patient Decision Aid. Evaluation was a theme which ran throughout all aspects of the PDA work. At the start of the programme, units were asked to undertake a baseline assessment of their experience of using a Patient Decision Aid and also to develop a means of evaluating the patient experience.

In spite of the challenging time frames, all sites were asked to ensure that where the tool was used, the experience was evaluated. Within Oxford University Hospitals NHS Trust evaluation of the PDA was undertaken through telephone interviews but this proved challenging and time consuming as sometimes patients were difficult to contact. The telephone results revealed 12 patients (50%) said they used the ESRF PDA after leaving the renal unit. The conversation sometimes prompted patients to take a look at the PDAs. One patient revealed that out of fear and as a way of coping he 'compartmentalises - when I leave the clinic I forget about my kidney condition and looking at the resources reminds me of what I am about to face'. He went on further to explain: 'I know I need to confront it but haven't felt ready yet'. This highlighted the importance of follow up.

4.1 Feedback from patients

Feedback from patients about the use of the PDA fell into two main categories: Content and IT based issues, and concerns and experiences.

Content of the PDA

Feedback from all trusts suggested that the evaluations have been largely positive. Patients had said that they liked the concept and felt it was helpful for using with friends and family. A patient thought that it would be helpful for her family as she found it 'too emotional to discuss face to face'. The illustrations were particularly well liked. A few patients and clinicians have commented that the language is pessimistic and the use of words like 'life expectancy',' effect on length of life' (especially when referred to in months) is worrying although honest. Pro-actively addressing and managing these difficult conversations relied on the skill of the practitioner, and emphasised the value and need for the advanced communication skills training, to support this. The balance of information and personalisation is a challenge, especially with conversations about prognosis. One aim of the PDA is to expose everyone to the same high level of information and so prompt and facilitate frank conversations about prognosis which might not otherwise happen.

One patient wrote that 'dealing in facts may suit a lot of people but often the initial need is for the psychological effects to be addressed' highlighting the need to utilise a range of methods to assist with decision making. This was echoed by a number of sites who reported that the PDA is a tool to assist but not replace the sound patient/clinician relationship. In one case, in an effort to improve the number of evaluations of the PDA tool, the website details were given to 11 established haemodialysis patients, requesting that they reviewed the information on the tool and then completed evaluation forms. At the time of completing the report only one of these patients had accessed the PDA tool, two others have been unable to log on to the tool (Heart of England NHS Foundation Trust).

The paper format of the tool appeared to be as positively evaluated as the web based tool.

Patients attending the group education sessions and individual sessions showed a good interest in using the PDA. Those that have used it found it “useful, very comprehensive, and good to sit down on your own and work through all the information.” One patient said they liked the fact it was “fool proof, gives clarity and can help you find the answer you are looking for.” A patient in one trust reported that they are reassured that the unit is active in promoting and innovating new ideas.

It has been found that when a patient has not wanted to, or is unable to use the PDA, it can still be used by family, friends and carers who are interested in participating in the decision making process. It helps that all interested parties are reading the same information from one source. This would be useful in a wider practice context, for example when meeting up with other health care professionals at multidisciplinary team meetings in the community.

Within Epsom and St Helier University Hospitals NHS Trust some patients did not like or did not find the large number of statistics useful, particularly around survival rates. On discussion they felt they would prefer to talk with their doctor or specialist nurse to enable this kind of information to be meaningful in the context of their own decision making.

In one unit, patients reported that the PDA was “very useful and supports the existing education programme.” In some cases patients and their carers preferred the paper format. The Lead Nurse for NHS Kidney Care supported and followed up the patients provided with the PDA either by telephone or in the Pre-dialysis clinic where questions and queries have been answered.

All the patients interviewed stated that the PDA could be useful. However they saw it as ‘value added information’ that could not replace the support and information provided by face to face care by their unit team. One established patient said that choosing the right option was such an “emotionally and physically challenging decision to make, it could not be achieved by sitting in front of a computer screen.”

There were many positive outcomes where patients had found the tool useful as it assisted them to understand the options open to them and also allowed them the ability to compare and contrast options.

Patients reported “liking the lay out of the information and that it was easy to use and understand”. The PDA served to support existing information being provided by the Pre-dialysis Nurse Specialist.

Feedback from some older Asian patients’ relatives have found the PDA very useful in assisting them to make decisions about their elderly relative’s modality.

IT experiences

Lancashire Teaching Hospitals NHS Foundation Trust reported that people who did not have access to the internet simply dismissed the idea of using the SDM sheets. Even patients with high intellectual ability seemed to prefer face-to-face discussion with a pre-dialysis nurse rather than using the PDA (Heart of England NHS Foundation Trust). This was echoed by Gloucestershire Hospitals NHS Foundation Trust, which reported that evaluation of the tool had identified that staff felt the wording was far too complex for most patients. Many patients were more interested in the opportunity to attend a regular education event organised by the pre-dialysis team that gave them the opportunity to talk to patients already on HD and PD, look at the equipment, and talk to members of the transplant team. Many patients have cited in the past that attending this event was useful in helping them decide which treatment would suit them best. The next event is to be held a few weeks after the end of the project.

Patients encountered some IT issues when using the PDA in their homes. Problems with logging on and trust IT systems were thought to be compounded by the service provider.

4.2 Feedback from clinical staff

Content

The PDA was an additional tool for use during consultation that enabled healthcare staff to support their patients to visualise the pathway and the options along the way. It raised the difficult questions and enabled a more proactive discussion.

Often the pre-dialysis staff used both the short and long form PDAs to complement existing education tools, and the feedback to date has been mostly positive. Patients are being identified and targeted more systematically and in a timely fashion.

Outpatient referral to PDA nurses was good. However some sites have found the short form quite time consuming to use – preferring to delegate this to the nurses to go through with the patients in more detail. All teams reported that staff seemed comfortable with the PDA and were willing to recommend it to suitable patients appearing to value it as an impartial, comprehensive and user friendly website.

On the whole, evaluation of staff experience suggested that staff in the low clearance clinic were quick to use the PDA. For the most part this has been signposting the PDA to people so that they can use it at home, though the shared decision making sheets have also been used as well.

Feedback from project teams during e-seminars highlighted that the language of the PDA was aimed at patients with higher level of literacy and educational attainment. This was a consistent theme across all teams.

Experience in Bart’s Health NHS Trust stated that some of those that have utilised the PDA found it contained too much information and at times gave inaccurate information. However, there have also been many positive outcomes where patients found the tool useful as it helped them to understand the options open to them and to compare and contrast options.

A common concern was that an online or written PDA, even if customisable to a certain extent, does not stop people making choices which might be technically impossible for them. For example some people cannot have peritoneal dialysis because of previous abdominal surgery. Or some people reading the PDA may come to the conclusion that they would like a transplant without being aware that they may not be fit enough to have one.

This concern was perhaps most prominent for conservative care. It was felt by many that the prominent position of conservative care in the PDA and some of the information presented might lead people to think that conservative care would be best for them when, in reality, their clinical teams would not consider it a good option.

The benefits of having clear, concise information about all available options for people with end stage kidney disease was also widely recognised. Concerns about the presentation and content of the PDA were usually balanced by using the PDA as one tool in the broader care pathway and by recognising the importance of personal relationships between patients and the clinical team.

Time commitment required to use the PDA

The process of making a decision often takes place over a period of time, and can take place both within and outside the clinical setting. Preparedness for decision making is variable and can take time to evolve. One of the advantages of the PDA is that it can be accessed repeatedly, at different times, and in different locations, and can be shared with anyone else. This does, however, make evaluation of its impact difficult, and impossible within the timeframe of this project.

It was highlighted that there was a great deal of information contained within the PDA and the lack of time or a sense of feeling over-burdened with information prevented patients from completing it. Some of those that had used the PDA found it contained too much information and at times gave inaccurate information.

Lancashire Teaching Hospitals NHS Foundation Trust reported that the vast majority of patients did not use the patient decision aid for reasons including low reading age, lack of IT access and difficulty with the paper based versions.

The PDA nurses at Aintree fed back their experiences of using the PDA:

“Navigating the ‘rightcare’ website was initially a bit difficult. There is a lot of information to look through…. this would require the user to be computer literate and determined. Unfortunately an obvious big problem is that those who do not have internet access and those that are not computer literate miss out completely on using this tool at home.

“It takes at least 1 to 1 ½ hours to use each aid but they are extremely user friendly and the summary at the end is valid and gives the patient all the information they need. The patients that I have guided through this process do feel more confident in making a decision regarding their care but I have noted that they still ask a lot of questions and require verbal conformation and discussion. My overall feedback is positive and the patients want to keep using the tool. I found it a brilliant tool to use to structure a tailored consultation for the patients.”

“The tool itself is excellent and very informative for the patients. I think accessing the page to find the tools can be a bit tricky for patients. I think patients need to be computer literate to navigate through the pages. The information it provides, can lead to a lot of questions’ that need to be answered. Also not all patients have an email address. This is not a problem whilst they are coming in to hospital, but could be if they are accessing at home. We have had plenty of referrals from Consultants which is good, staff on the ward are aware of the role and referring patients also.“

Resourcing the project

All project teams reported that the time scale was a major challenge as it took time for placement of staff and acceptance onto the project.

In some units there was a delay in back-filling for ward nurses who were employed as PDA nurses. This pushed back enrolment on training courses, such as advanced communication skills.

Recruitment or secondment of staff is always time consuming and within a four month project this posed a big challenge to teams. Often the result of this was that driving and delivering the project was undertaken by existing team members, which placed enormous pressure on existing workloads.

As expected, consultants often found it difficult to spend a lot of time discussing the website information with patients, but were happy for the advanced kidney disease specialist nurses to use the PDA when meeting their patients. One future challenge may be to sustain the current level of engagement with clinicians in the long term.

5 Progress and achievements to date

Trusts were invited to provide feedback on their progress and achievements to date. Results included:

- Expansion of existing IT has allowed for central capture of patient decision making and their modality choice in our renal database, so more accessible to all staff concerned.
  (Addenbrooke's Hospital)
- Educating the ward staff in the concept of shared decision making and the tools used. Posters and verbal presentations made by the PDA nurses to colleagues.
  (Aintree University Hospitals NHS Foundation Trust)
- All pre-dialysis patients attending monthly education forum are informed about the PDA and the importance of the need to engage and empower them in all decisions about their care. The details and web address for the PDA are shown. Feedback that some older Asian patients relatives have found the PDA very useful in assisting them make decisions about their elderly relative's modality.
  (Bart's Health NHS Trust)
- Informal presentation for ward staff to engage wider staff groups, to catch patients admitted to the ward that will not be seen in outpatients.
  (North Bristol NHS Trust)
- Provision of PDA web cards in consulting rooms encouraged clinicians to direct patients to the PDA.
  (Brighton and Sussex University Hospitals NHS Trust)
- Identification of people for whom the PDA is appropriate and offering them the PDA has been incorporated into our low clearance clinic reasonably seamlessly.
  (King's College Hospital NHS Foundation Trust)
- The patient decision aid will be part of the routine information offered at face to face interviews with patients and the pre dialysis team.
  (Lancashire Teaching Hospitals NHS Foundation Trust)

- Renal nurse present in clinics with specifically identified patients to see, to help educate the patients at the right time, reducing inappropriate referrals.
  (The Royal Liverpool and Broadgreen University Hospitals NHS Trust)
- Three of the unit's 'expert patients' have been asked to use the PDA and given extensive qualitative reviews on it.
  (Epsom and St Helier University Hospitals NHS Trust)
- The PDA will be used as an aid in conjunction with existing processes. The existing bespoke ESRF education service will continue and the PDA will be an additional and useful resource.
  (Royal Cornwall Hospitals NHS Trust)
- Added to the education pathway plan to have the PDA and SDA to be fully integrated within the next four months.
  (Gloucestershire Hospitals NHS Foundation Trust)
- Embedded the PDA/SDM into the pre-dialysis pathway such that all patients receive information about it with appropriate links.
  (Sheffield Teaching Hospitals NHS Foundation Trust)
- All relevant letter templates, local unit web pages, information meetings with patients, information leaflets refer to the PDAs with information on what they are and how to access them.
  (Norfolk & Norwich University Hospitals NHS Foundation Trust)
- Re-evaluated the pre-dialysis pathway and included the PDA as an available tool. A successful way to embed the use of the PDA within the pre-dialysis nursing team.
- **(Oxford University Hospitals NHS Trust)**
- Incorporated the use of a regional Kidney Care Plan for patients in pre dialysis - to expand this to patients on dialysis this year.
  (Wirral University Teaching Hospital NHS Foundation Trust)
- Provision of PDA web cards in consulting rooms has encouraged clinicians to direct patients to the PDA.
  (Brighton and Sussex University Hospitals NHS Trust)
- A flow chart was developed to assist in the referral of patients to the PDA.
  (Heart of England NHS Foundation Trust)
- Engaged with local patients from the outset and have the PDA incorporated into current practice. Special focus was on patients of South Asian origin, who were able to engage with the help of family and friends.
  (Bradford Teaching Hospitals NHS Foundation Trust)
- Implementation of the Right Care PDA in to the pre-dialysis education pathway.
  (Newcastle upon Tyne Hospitals NHS Foundation Trust)
- CKD nurses to lead on shared decision making and provide consistent follow up, information and education in the OPD setting.
  (Plymouth Hospitals NHS Trust)
- Auditing all patients that already on dialysis and again highlighting patients that would be suitable or may wish to review their original modality of choice.
  (Colchester Hospital University NHS Foundation Trust)

- Posters were designed and displayed in clinic areas to inform patients about the PDA and this also asked for volunteers to evaluate their experience**.**
  (Imperial College Healthcare NHS Trust)

6.0 Sustainability / Going Forward / Next Steps

All services were keen to continue using the PDA after the life of the projects. There was a widely held belief in the value of the tool in supporting patients to make informed decisions. Trusts reported that they would continue to use the PDA and continue promoting its use in the pre-dialysis population, for unplanned starters on dialysis, and those who have chosen not to have home therapy. It would become part of the dialysis educational toolkit and will be integrated into the existing materials already in use.

The ability to identify 'values and trade-offs' was felt by the team in Oxford to enhance the quality of the decision making process. The resulting decision was more likely to be the right one.

Participation in the project was evaluated positively by all units who felt it has generated real debate about shared decision making and how well the units are doing to promote this.

The PDA has been included in education and training programmes, such as in an 'in house' nurse education/training programme. It is also being used as a tool to inform other health professionals involved in patient care e.g. care home staff.

7.0 Conclusions

The short timeframe of the programme has posed many challenges to the project teams. It has meant that evaluation data to date reflects experiences behind the process of implementing the tool and structures developed to support its inclusion in the patient pathway, rather than results from patients. However evaluation has so far been predominantly positive. It was felt that there is a place for the tool in the library of patient information resources and clinical tools, but it is not an answer on its own. Using the tool with patients demanded greater time than predicted and many patients wanted to go through the tool with their clinician, rather than it being a resource they used at home. Teams found as a group that patients required more support to go through the process than initially thought.

Data from Right Care shows that, over the course of the project, there was a significant increase in the number of times the renal PDA was accessed on their website – from 369 hits in September 2012 to 2,016 in February 2013. This data also shows that a very high proportion (46% in January) of total hits on the Right Care SDM site were to view the renal PDA. It is not possible to specify who is accessing the site but these numbers suggest that patients and staff are using the site and are interested in what the PDA offers.

The lack of availability of the information in other languages, especially in areas of high ethnic diversity, was felt to be a barrier to usage, although in practice many units had felt that where there was an adult within the family who spoke English, usage of the tool had not been impossible and had in fact generated shared discussion.

The issues with IT compatibility and procurement within trusts has meant that some project teams were delayed in getting started. Procurement processes have meant some units spending more on the equipment and waiting longer to receive it than if they had gone to a local supplier.

Feedback suggested that the projects have managed to bring teams together. Teams had a common objective. The use of online PDAs is increasingly relevant as more and more people become IT literate. The mobile app is appropriate and will be hugely popular with smartphone users. Bringing all the information together and being able to compare it side by side makes it easier to discuss with patients and they say it is easier for them to see options compared in this way

One unit felt strongly that the idea that patients take control of their own healthcare is something that needs to be embedded in order to continue this work. The patients need to be the ones prompting the doctors with their ideas and thoughts for the future.

Recommendations for use of the PDA with patients in practice:

- Patients' information requirements are variable and it is not easy to predict who will want to use the PDA and who will not.
- Not all people are IT literate and that is a factor across all ages and communities.
- Teams need to be very aware of the level of health literacy within their communities in order to understand the best way to implement the PDA.
- Whilst translated versions of the PDA may be desirable, the PDA can have a very positive impact for patients where one or more people in their family can access and read it.
- The PDA is designed for use by patients outside the clinical setting. Many patients however want to use it (or can only access it) in the clinical setting. Additional time is needed when using the PDA in clinic with patients.
- Some of the content of the PDA can be described as challenging and explicit. The tool enables patients to read, review and discuss that information at a speed that suits them.
- The PDA is a very useful tool but cannot be (and is not intended to be) a substitute for personal relationships between patients and clinical teams.
- Time taken to establish use of the PDA and to bring about a change of working patterns or culture was more than initially anticipated: scoping and set up times need to be reflected in project plans and timeframes.