How to introduce a shared decision making approach

getting started... a guide for primary care and community teams

How to introduce a shared decision making approach
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### Annexe

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Shared decision making used in a consistent and effective way can ensure greater ownership and engagement from patients, reduced levels of major surgery and emergency admissions and improved satisfaction and experience for individuals and potential financial savings.

Shared decision making, self care and self management are all ways in which the individual can gain greater choice and control over their condition.

**Example**

This approach can be used by practice and community nursing teams working with terminally ill individuals to provide support and input based around the individual and their family’s preferences. The individual and their carers can be involved fully in considering options, including the level of intervention (i.e. care in hospital versus a lower level of intervention at home), and the ‘end of life’ decisions to enable the person to have the end of life they wish.

This approach also needs to be considered as new pathways are developed, to introduce prompts to encourage shared decision making at key points for both the practitioner and the individual.

**Example**

A person with knee osteoarthritis can be supported through the use of a decision aid to become fully aware of the alternatives to surgery before being referred to see an orthopaedic consultant. Having worked through the decision aid, they can ask themselves: do they want surgery? Are they fit enough for surgery if they do want it? They can be more aware of the work they will need to do post surgery to gain the most benefit. They can talk through these with their GP/physiotherapist to enable them to reach their final decision.

The resource explains what shared decision making is – and how it links into other person-centred approaches such as personalised care planning, self care and self management. It outlines how to introduce a share decision making approach, with references and web links for shared decision making, personalised care planning and self management. There are also links made to the personalisation approach within social care and local authorities.

Each section gives an overview of a particular aspect of shared decision making, together with core references which are linked to that theme. Further resources and links are given in the Annexe.

This resource is one of three developed for introducing shared decision making:

- **Shared Decision Making; Getting Started ...A guide for primary care and community teams**, is a detailed reference for clinical commissioning groups and for training purposes.

- **Shared Decision Making; Getting Started ...A short guide for practitioners**, is a reminder of the purpose, principles and practice from the above resource.

- **Shared Decision Making; A resource for commissioners**, is a high level guide to take commissioners through the key areas that they need to consider, when supporting a shared decision making approach locally.

These resources have been produced for Yorkshire and Humber – part of NHS North of England – to raise awareness of shared decision making and its importance in embedding in health care cultures.
Shared decision making forms part of the wider personalised approach to providing health and social care and support. The principle is based on the recognition that the individual and professional both have an important part to play, and both bring equal and differing knowledge to any decision making process. Shared decision making involves the practitioner supporting and informing the individual, so that together they can make an informed choice about which way forward is going to be best for that person – based on the individual’s values, experiences and preferences.

Shared decision making as an approach can be used in a wide variety of settings and for many decision making processes. The individual concerned will need to have sufficient cognitive and communication abilities and a wish to work on this basis – and the individual’s condition needs to be appropriate.

In recognition of the equal partnership, co-production approach, the term patient will rarely be used within this resource, unless quoting from a reference.

How does shared decision making link into personalised care planning and self care and management?

Definitions vary: some of the above are taken from NHS Midlands and East ‘Delivering Sustainable Care’ ([https://www.eoe.nhs.uk/page.php?area_id=16](https://www.eoe.nhs.uk/page.php?area_id=16)) and King’s Fund Case Management: what it is and how it can best be implemented ([http://www.kingsfund.org.uk/publications/case management](http://www.kingsfund.org.uk/publications/case management)).
What are the principles of shared decision making?

‘No decision about me without me’...

- Active engagement of individuals and/or their carers in making informed decisions about their health care, which can be used in many clinical consultations
- A holistic approach which is built around the priorities of the individual, their lifestyle and preferences
- Informing the individual about their condition, about the treatment and/or support options available and the benefits and risks of these
- Basing any decision on a mutual understanding of the available information/evidence

**PRACTITIONER’S PERSPECTIVE**

**INDIVIDUAL OR CARER’S PERSPECTIVE**

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(adapted from Right Care about the Shared decision making programme ‘What are we sharing?’)

http://www.rightcare.nhs.uk/index.php/shared-decision-making)
What are the potential benefits of shared decision making?

- Reduced use of high-cost services and unplanned admissions and complications
- Fewer individuals choosing major surgery or elective surgery in general
- Helps individuals choose the treatment or support which is most closely aligned to their personal values, principles and preferences
- Potential to increase an individual’s commitment to the chosen approach and in the case of medication or self care increased adherence and understanding
- Improved confidence and coping skills
- Clearer expectations of roles and responsibilities and improved relationship with the individual
- Improved clinical outcomes
- Improved clinical safety
- Increased attendance at appointments
- Reduced duplication of tests
- Evidence that decision aids can improve individual experience and that the shared decision making approach generally, can improve an individual’s satisfaction and experience
- May provide a good source of information for commissioners on the needs and preferences of individuals, to inform future service model development. There is potential to contribute to managing demand and reducing inappropriate local variation if used effectively and consistently.

Core Reading Suggestions

- Making shared decision-making a reality: No decision about me, without me (Kings Fund, July 2011)
  http://www.kingsfund.org.uk/publications/nhs_decisionmaking.html
  A wide-ranging core paper covering the policy context for shared decision making, the potential clinical and non-clinical benefits, ethical and professional issues involved in developing shared decision making, and potential barriers to adoption in the real world. The authors’ highlight that there is a sound ethical basis for shared decision making: ‘The most important reason for practising shared decision-making is that it is the right thing to do’.

- Shared Decision Making: essential reading (QIPP Right Care, Dec 2010)
  A digest of systematic review papers relating to shared decision making, plus the Kings Fund report and other resources included in this guide.

- Analysis: Implementing shared decision making in the NHS (BMJ 2010;341:c5146)
  http://www.bmj.com/content/341/bmj.c5146
  At least three conditions must be in place for shared decision making to become part of mainstream clinical practice:

    - ready access to evidence based information about treatment options;
    - guidance on how to weigh up the pros and cons of different options;
    - and a supportive clinical culture that facilitates patient engagement.

- Good Medical Practice (consultation draft), (GMC, October 2011)
  New draft guidance from the General Medical Council (GMC) for all registered doctors:

    - Doctors ‘must support patients in caring for themselves to empower them to improve and maintain their health’.
    - This may include encouraging patients, including those with long-term conditions, to stay in or return to employment or other purposeful activity.
    - Doctors may also advise patients on the effects of their life choices on their health and well-being and the possible outcomes of their treatments.
Core Reading Suggestions

- **NICE clinical guidance 136 (CG136) Service user experience in adult mental health** (NICE, December 2011).
  
  http://www.nice.org.uk/guidance/qualitystandards/service-user-experience-in-adult-mental-health/index.jsp
  
  Includes the following standards:
  
  - Standard 3 - People using mental health services are actively involved in shared decision-making and supported in self-management.
  
  - Standard 7 - People using mental health services understand the assessment process, their diagnosis and treatment options, and receive emotional support for any sensitive issues.

  
  
  Assesses practical, ethical and professional issues involved in shared decision making in relation to medicines management and warns that simplistic approaches to its implementation may result in sub-optimal outcomes for patients.

Not all of the gap between ideals and practice should be seen as mere ‘resistance’ or ‘drag’ on the part of healthcare professionals. In particular:

- The right infrastructure and tools need to be put in place if calls for widespread partnership working are to be realistic;

- Some of the gap between ideals and practice stems from valid concerns and from the inherent complexities of involvement- or partnership-related values.
When to use shared decision making?

**Deciding on...**

Shared decision making can and should be used in many clinical situations including:

- Making a lifestyle change or taking responsibility for some aspect of treatment
- Major treatment decisions, e.g., agreement to undergo major surgery
- When there are several potential options available for treatment or support
- Personalised health/care planning: focusing on setting and achieving goals for the outcome for the individual (usually for an individual with long term condition(s))
- Discharge planning
- Introducing or changing medication
- Screening or diagnostic tests
- Advance care planning (end of life care, dementia care, etc)

(Adapted from the King’s Fund ‘Making shared decision-making a reality: No decision about me, without me’ July 2011 [http://www.kingsfund.org.uk/publications/nhs_decisionmaking.html](http://www.kingsfund.org.uk/publications/nhs_decisionmaking.html))

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**Core Reading Suggestions**

- **The Right Care programme**
  - A national workstream in the Department of Health Quality Innovation Productivity and Prevention programme (QIPP). This is a core website to gain further understanding of shared decision making, how it links into wider initiatives around long term conditions and the commissioner’s perspective.

  It focuses on increasing value and improving quality through addressing variation and in particular unwarranted variation, through promoting the use of health investment tools such as programme budgeting, and through sustainable systems and population planning.

  There are five workstreams:
    - Population Planning and Programme Budgeting
    - Clinical Networks and Systems of Care
    - Better Value Clinical Practice
    - Shared Decision Making
    - Population Medicine

  - **Shared decision making workstream** (part of the national programme above)
    - The workstream within Right Care focuses on managing the constantly growing demand for healthcare where demand is managed by informed and empowered patients making rational healthcare decisions. Led by NHS Midlands and East of England. ([https://www.eoe.nhs.uk/page.php?page_id=2165](https://www.eoe.nhs.uk/page.php?page_id=2165) provides a further link to shared decision making resources).

    The three key elements of the programme are:
    - Patient Decision Aids and Patient Decision Support: self administered informational tools that prepare patients for making informed decisions about medical tests or treatments
      - Online decision aids for specific conditions
      - Decision support provided by NHS Direct and potentially other organisations
    - Embedding shared decision making in practice
      - tools for practitioners (e.g., prompts in referrer systems etc)
    - Creating a receptive culture for shared decision making:
      - National engagement programme
      - Tools for commissioners to embedding of shared decision making in contracts
Shared decision-making within a personalised care approach

The following resources refer to personalised care and are not specific to shared decision making; however, they may provide useful context for practitioners and help to set the scene for the development of shared decision making for relevant patient groups and clinical conditions.

**Personal Health Budgets learning network**
http://www.personalhealthbudgets.dh.gov.uk
Central Department of Health resource for personalised budgets and providing links to other personalisation information and resources.

**Key elements of personalised care planning in long term conditions and personal health budgets** (DH/ Helen Sanderson Associates, June 2010)
A useful overview of the key elements of personalised care planning for people with long term conditions, although it does not cover shared decision making in detail.

**Improving Care for people with long term conditions – Information Sheets** (DH, November 2010)
A series of information sheets for those delivering personal health budgets, allied health professionals, health trainers and anyone supporting individuals with long term conditions.

Shared decision making is not covered in detail, sheet 1 includes a section on planning and preparing for a discussion with patients/carers in the development of personalised care plans.

- Information sheet 1: Personalised care planning
- Information sheet 2: Personalised care planning diagram
- Information sheet 3: Care coordination
- Information sheet 4: Managing need and assessment of risk
- Information sheet 5: How information supports personalised care planning and support for self care
- Information sheet 6: What motivates people to self care
- Information sheet 7: Goal setting and action planning as part of personalised care planning
- Information sheet 8: End of life care and personalised care planning
In the consultation

Possible questions to encourage individuals to ask:

- What are my options?
- What will happen if I choose to do nothing?
- What are the pros and cons of these options? (benefits and risks)
- How likely are these to happen?
- What else do I need to know before making my decision?

What’s it like for the individual working through the decision aids?

“I was diagnosed some years ago with a number of long term health conditions, with a poor long term prognosis... I was particularly interested to see how the Patient Decision Aid would fit in with the ethos of self-management. The Patient Decision Aid respectfully and gently guides you through all aspects... I felt it was like having a long, unhurried session with a top knowledgeable specialist, plus the benefit of extra advice from the videos, if you wish. The aid really relates to you as an individual, and how the condition affects you... to think what is important to you in deciding which treatment you prefer, and what is right for you. You then have a summary, a personal record of your journey, which you can print off to share with your health professionals, or just keep for reference.”

“Actually, it makes you think more about your condition and how best to help yourself. Instead of you telling me what I have to do, I do what is right because of the information you have given me previously – it is like being your own physician. If I am having slight hypo I can tell straight away and I know what to do exactly.”

Summarised quote from an individual in Yorkshire and Humber; follow the link to watch the full interview – shared decision making within personalised care planning: http://www.yorksandhumber.nhs.uk/what_we_do/improving_patient_care_and_service_quality/informing_decisions_improving_care_/personalised_care_planning

Summarised quote from an individual from the East of England, follow the link https://www.eoe.nhs.uk/page.php?page_id=2165 for the full interview.
Core Reading Suggestions

- **Healthtalkonline.org: Shared Decision Making**
  (Health Experiences Research Group, April 2011)
  Comprehensive set of patient interviews collected by The Health Experiences Research Group (University of Oxford) on their experiences of decision-making and the place of shared decision making in a range of contexts.

- **Engaging people with MS in decision-making: The concept of evidence-based patient information**
  (Way Ahead 2010;14(4):6-9)
  [http://www.mstrust.org.uk/professionals/information/wayahead/articles/14042010_03.jsp](http://www.mstrust.org.uk/professionals/information/wayahead/articles/14042010_03.jsp)
  Discussion paper outlining the potential advantages of providing people with multiple sclerosis with evidence-based information as part of an ongoing shared decision making approach.

- **Partners in Care: a guide to implementing a care planning approach to diabetes care**
  (National Diabetes Support Team, February 2008)
  A guide to implementing personalised care with a section on the role of shared decision making in achieving quality care plans, and practical suggestions to support shared decision making.

- **Patients’ perceptions of sharing in decisions: a systematic review of interventions to enhance shared decision making in routine clinical practice.**
  The systematic review looks at interventions from the patient perspective. It found that a multi faceted approach, including educating health professionals about shared decision making and patient-mediated interventions such as patient decision aids, appear promising for improving health professionals’ adoption of shared decision making in routine clinical practice.

- **Expert Patients**
  [http://www.expertpatients.co.uk/about-us/what-we-do](http://www.expertpatients.co.uk/about-us/what-we-do)
  A community interest company providing free training aimed at helping people who are living with a long-term health condition to manage their condition better on a daily basis. Includes training on communicating with professionals (which could support the development of effective shared decision making for this group).

- **Patient questions in shared decision making**
  [http://www.cardiffandvaleuhb.wales.nhs.uk/whatisit](http://www.cardiffandvaleuhb.wales.nhs.uk/whatisit)
  Making sure people get the answers to the questions and allowing them to explain what is important to them will make sure that individuals are involved in shared decision making,
Introducing shared decision making locally

As shared decision making is an integral part of implementing personalised care planning, a small number of practices implementing personalised care planning across Yorkshire and Humber took part in structured interviews. The following are some of the key learning points:

**The Team...**

- The practice needs to recognise that it wants to work more closely with their patients in a partnership approach.
- Senior staff in the practice need to support the approach and be actively involved.
- Champions – each practice should identify a lead nurse or GP to support this approach.
- The champion should engage everyone involved early on.
- Training is important in understanding the different language to use, questions to ask and the change in roles and responsibilities – e.g. in developing coaching/motivational interviewing styles – having the right skills is important.
- Who to try it out on first? The practice may chose a discrete group of patients initially to try out the approach.
- Good communication is essential both within the practice and with patients. It is likely that some patients will need reminding about this style of approach.
- The practice website can give information/make links to relevant conditions.

**Systems and Processes...**

- Flexibility in approach in using any tools is essential, as is remembering that the individual’s views are central to success.
- Use of different appointment timings: Shorter appointments for people being seen for one condition, longer for those with multiple conditions.
- Allow more time for the initial appointment – longer first appointments means less time may be needed later on and also any tests can all be done in one session.
- Tests – if required, arrange for these to be done in advance of any care planning session. Ensuring that the individual has received the results of any test results (e.g. where regular tests are carried out relating to a long term condition) in advance of an appointment allows the person to think through any questions in advance.
- Work through the relevant pathway and processes before making the changes, even if they need further changes later.
- The approach has worked well for diabetes, smoking cessation and weight loss.

**The Individual...**

- Good communication within the practice and with patients is essential. Some people will need reminding about this style of approach and that they need to bring their information with them.
- Developing an accurate patient information pack about shared decision making, which can be sent out in advance, outlining the changes that people can expect to experience.
- Allowing time for people to understand and accept and support the changes. Patients have spent many years learning how to be patients. Cultural change is slow for everyone!

“How you plan and what happens in practice can be two different things – stay flexible.”
Core Reading Suggestions

- **SHA Shared Decision Making Projects** (NHS Networks)
  Links to outputs from pathfinder projects on development of shared decision making including ‘Supporting Shared Decision Making’ below.

- **Supporting Shared Decision Making: a pathfinder project for NHS North West** (Picker Institute Europe, August 2011)
  Report of a qualitative research project with clinicians and patients on the perceived benefits of shared decision making and the issues involved in its development in practice.

- **What does a patient engaged organisation look like and how do we get there?: Clinical and staff perspectives on shared decision making and information giving** (Herts Valley Clinical Commissioning Group, Sep 2011)

- **Big Change, Small Steps - what does a patient engaged organisation look like and how do we get there?** (InHealth Associates for Southend Estuary Clinical Commissioning Group, July 2011)
  Two projects leading to recommendations on how to build patient participation into the work of clinical commissioning groups based on work by clinical commissioning groups in NHS East of England;
  - These projects focused on improving patient engagement at organisational level in commissioning strategy and practice delivery (outside the scope of this resource guide) as well as on the development of organisations able to deliver shared decision making with patients at an individual level.
  - Increasing shared decision-making in the clinical encounter is seen as one strand of an overall strategy to improve patient engagement more generally.

- **Improved patient access to their own clinical information will be a necessary support to shared decision making**

- **Existing tools and support for shared decision-making need to be collated and shared (largely through existing communication channels), including the Expert Patient Programme, carers’ champions in each practice and a directory of voluntary sector support organisations.**

- **The MAGIC programme** (Health Foundation)
  The MAGIC programme is working with frontline health professionals and their priority projects across the UK to test how to embed best practice and overcome the barriers to change. The Health Foundation works to support making healthcare more patient-centred and influencing more healthcare professionals to give patients the choice and involvement.

- **Understanding and shaping culture change: implementing personal health budgets** (NHS Y&H, 2011)
  A practical and accessible guide to leading culture change in practice: produced for use in developing personal health budgets but also applicable to development of shared decision making in the wider context, e.g. in relation to the conditions covered by existing online decision aids.

- **Teleconsultation and telemonitoring**
  Practical guides to using assistive technology in new service models: again, not directly related to shared decision making and potentially helpful in developing an ongoing shared decision making approach with appropriate patient groups.
What is needed?

All shared decision making builds on the existing communication and consulting skills of the practitioner. This approach makes the individual’s and/or carers views and preferences the primary focus of the consultation.

- Good record keeping and recording of information – decisions made, risk agreement, review
- Accessible information and records for both the individual and professionals
- Consulting style of practitioners includes
  - Empathy and relationship building
  - Listening skills
  - Flexibility
  - Ability to ask open questions
  - Translating the individual’s words into goals where helpful
  - Supporting the individual to think through the pros and cons
  - Informing, educating and communicating risk
  - Promoting self care and management
  - Making the decision
  - Documenting the decision, agreed actions, ongoing roles and responsibilities and any risk sharing agreement
  - Working with individuals unwilling to engage in shared decision making

‘Patients need different information, not more of the same, and there is an urgent need for more honesty about the limitations of medicine and the uncertainties of medical knowledge. Patients need to be aware of the possibility of both benefits and harms and helped to make decisions based on their own valuation of the various possible outcomes.’

(Adapted from the King’s Fund ‘Making shared decision-making a reality: No decision about me, without me’ July 2011 (http://www.kingsfund.org.uk/publications/nhs_decisionmaking.html) and From Involvement, shared decision making and medicines, Royal Pharmaceutical Society November 2011 (http://www.rpharms.com/news-story-downloads/rpsresearchreport.pdf))

continued overleaf...
Strategies for practitioners:

- A decision needs to be made and that there is no ‘best’ choice
- Do nothing or maintain the status quo is also an option
- Discuss the pros and cons of each – the benefits and risks
- Elicit the person’s ideas, concerns and expectations about their options, their benefits and concerns by asking open questions
- Possible questions to ask the individual:

  - What do you know about the treatment or self-management support available?
  - What do you expect from the treatment or support for your condition?
  - Do you have all the information you need to weigh up the options?
  - What aspects of the treatment or procedure are you most concerned about?
  - How do the benefits of each option compare? How do the risks compare?
  - Thinking about this decision, what is the most important aspect for you to consider?
  - Who else do you need to talk to, before making this decision?
  - Having got all the information, is there anything else you need to think about before making a decision?

Adapted from the article Shared decision making: really putting patients at the centre of healthcare BMJ January 2012

Summary...

Shared decision making involves ensuring that the individual and/or carer views and preferences are the focus of the consultation. When used consistently and effectively, shared decision making can result in gains for the individual, the practitioner and commissioners.
Shared Decision Making Decision Aids

http://www.nhsdirect.nhs.uk/DecisionAids

Links to online decision aids (hosted by NHS Direct) for:
- Advanced kidney disease
- Benign prostatic hyperplasia (BPH).
- Cataracts
- Localised prostate cancer
- PSA testing
- CVS and amniocentesis
- Breast cancer
- Knee arthritis
- Osteoarthritis of the hip

Core Reading Suggestions

Consultation styles
http://www.healthtalkonline.org/Improving_health_care/shared_decision_making/Topic/4038
Useful discussion within a more general resource (see Introducing shared decision making locally on page 12) looking at styles of consultation and their usefulness in shared decision making.

Shared Decision Making: really putting patients at the centre of healthcare
This paper by the BMJ outlines best practice examples and strategies that clinicians and their organisations can use to support patients to become involved in decision making. A useful core paper for clinicians.

Partners in Care: stories about NHS patients and their doctors (BMA, 2009)
A series of anecdotal articles about successful doctor-patient relationships. It is not specifically directed to the development of shared decision making, but potentially useful as a means of discussing options for changes in practice to support shared decision making within the practice.

Medicines management — pharmacy input to compliance
http://www.npc.nhs.uk/patients_medicines
http://www.npc.nhs.uk/local_decision_making/guiding_principles.php
The National Prescribing Centre has produced high level principles in terms of making local decisions about medicines which also references the input of the individual.
All the links given within the resource are correct at the time of publication, in the future some specific links may change, so the home page or equivalent links are given below for the core national resources.

### Right Care


The Right Care website focuses specifically on shared decision making and Delivering Right Care for Patients focuses on three interdependent elements of Shared Decision Making: Patient Decision Support; and Embedding in Practice: Creating a receptive culture for Shared Decision Making within practices and teams.

### Shared decision making decision aids


Links to online decision aids (hosted by NHS Direct) for: Advanced kidney disease, Benign prostatic hyperplasia (BPH), Cataracts, Localised prostate cancer; PSA testing, CVS and amniocentesis, Breast cancer; Knee arthritis, Osteoarthritis of the hip.

### BMJ Shared decision making: really putting patients at the centre of healthcare


The BMJ website has several useful articles on shared decision making including systematic reviews.

### Kings Fund

Making shared decision-making a reality: No decision about me, without me (Kings Fund, July 2011)


This paper provides a valuable overview of shared decision making and links to existing work nationally. It also provides more detailed coaching-style questions for practitioners to use.

### NHS East of England


NHS East of England have produced many resources around shared decision making and personal health planning. A useful website as a starting point to look at how other places are introducing a more personalised approach to care and support.

### Department of Health


All the key regulations and guidance and discussion papers relating to personalisation, shared decision making and personal health budgets are available on this website.
The following section highlights the policy about what needs to be in place for successfully supporting a shared decision making approach.

- **The Operating Framework for the NHS in England 2012/13** (DH, November 2011)
  Sets out the planning, performance and financial requirements for NHS organisations in 2012/13 based on the current NHS strategic vision.
  **Key points:**
  - Commissioners are required to improve patient empowerment including the expansion of shared decision making (sections 3.22 – 3.25) and therefore practices/practitioners need to be aware of and preparing to introduce this approach.
  - PCT clusters should prepare for all patients with NHS continuing care to be offered a personal health budget for relevant aspects of care by April 2014.
  - Local delivery of personal health budgets should form part of transition planning by PCT clusters and Clinical Commissioning Groups (CCGs).

- **White Paper: “Equity & Excellence: Liberating the NHS”** (DH, July 2010)

- **Health and Social Care Bill 2011 (draft)**
  Proposals for transformational culture change across the NHS, including building a greater emphasis on partnership between patients and professionals in both commissioning and delivery of care to the individual.
  **Key points:**
  - Shared decision making will become the norm: ‘no decision about me without me’.
  - Shared decision making relates to decisions made about individual care delivery and also to strategy and commissioning development and co-production of healthcare.

- **Liberating the NHS: Legislative Framework and Next Steps** (DH, December 2010)
  **Key points:**
  - “Commissioners will need to make pathways flexible enough to allow patients the scope to make decisions about their care, using decision aids where appropriate, and to promote self-care.”
  - The NHS Commissioning Board will have a duty to have regard to the need to promote the involvement of patients and their carers in decisions about the provision of health services to them.

- **NHS Constitution** (DH, Jan 2009)

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Access for patients to information is essential to enable them to make choices about their care. This will include increased access and control by patients over their own care records and information on the performance of providers.

Shared decision making will include decisions about service model(s) to be delivered to the individual and the provider(s) who will deliver it.

Measuring outcomes for patients (including their participation in decision-making) will be at the heart of performance management of the NHS in future, as opposed to a focus on the measurement of individual processes.

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continued overleaf...
Handbook to the NHS Constitution (DH, March 2010)

Sets out the principles and values of the NHS in England and the rights and responsibilities which patients, staff and the public owe to one another to ensure that the NHS operates fairly and effectively.

Key points:
- Patients have the right to make choices about NHS care and to information to support these choices.
- The options available to patients (i.e. the scope of the choices available to them) will develop over time and depend on individual needs.

High quality care for all: NHS Next Stage Review final report 2008

Endorsed the need to increase patient empowerment in NHS care, and was a major influence on the development of the NHS Constitution.
This section identifies some of the wider web links which provide useful context for shared decision making. It includes the most recent information on the local authority approach to personalisation.

**USING A PERSONALISED APPROACH**

- **Nurturing Power of Personalised Care**
  
  New draft guidance from the General Medical Council (GMC) says doctors “must support patients in caring for themselves to empower them to improve and maintain their health”.
  

- **In Control**
  
  [http://www.in-control.org.uk](http://www.in-control.org.uk)
  
  In Control is a social enterprise operating an extensive community network, working for change and to provide people with the knowledge, power and tools to control their support. They were pioneering personalisation and self directed support ten years ago and have a number of very useful publications available ranging from reports and discussion papers through to books, DVDs and toolkits. The resources cover all age ranges; children through to adults across health and social care.

**PERSONAL HEALTH PLANNING**

- **Personal Health Planning**
  
  
  Personal health planning is way of empowering people with long term conditions to be able to take greater ownership and responsibility for their care and to have more control over the management of their long term condition.
  
  The personal health plan is owned by the individual and it is up to each person what information they wish to include. The content of the personal health plan is likely to change over time.
  
  [http://www.cambridgeshire.nhs.uk/Your-health/long-term-conditions.htm](http://www.cambridgeshire.nhs.uk/Your-health/long-term-conditions.htm)

- **Personal health budget**
  
  This link is to the learning community for professionals directly involved in the health budgets programme.
  
  
  **Key points:**
  
  - People to have greater choice and control over their care; and the fourth interim evaluation report on the pilot.
  
  - NHS Choices: [www.nhs.uk/phbcommunity](http://www.nhs.uk/phbcommunity)
  
  - Personal experiences and stories, plus the launch of the personal health budgets DVD “…Stories from the pilot programme”.
  
  - Programme update; working with people who have budgets, frontline practitioners and providers.

continued overleaf...
Key elements of personalised care planning in long term conditions and personal health budgets
Discussion paper June 2010

Key Points
- Explores best practice in care planning for long term conditions, and how this might help in developing care plans for personal health budgets.
- Identifies common elements of care planning from a range of initiatives focusing on long term conditions, as well as identifying additional elements that might be required for personal health budgets.
- Recognises the development of new approaches to personalised care planning is a crucial component in the implementation of effective personal health budgets.
- Offers a summary of learning from long term conditions, with the aim to provide a useful framework to pilot sites when approaching the planning of personal health budgets.

PERSONAL CARE PLANNING

Personalised Care Planning

Personalised care addresses each patient’s range of needs, and recognises the issues beyond medical needs that can impact on health and well-being. It can involve GPs, practice nurses, consultants, community matrons, social workers and more, and aims to provide the support, information and technology needed to empower patients to manage their own conditions, and retain control of their own lives.

http://www.southeastcoast.nhs.uk/Our%20Work/Personalised%20care.htm

Care and support planning for long term conditions

A quality framework to support commissioners and providers to implement care planning is a tool for healthcare professionals to use to benchmark existing services and identify any gaps/areas that need to be looked at to deliver high quality care planning. It includes a workforce guide developed by NHS East of England to help key workers and managers identify and develop the skills, knowledge and behaviour required to implement personal care planning, as well as national guidance.

http://www.southeastcoast.nhs.uk/Our%20Work/Personalised%20care.htm

Nursing Times web link

Various links on personalised care plan pilots up and running.

SELF CARE

The seven principles that underpin Self Care:
- Ensure individuals are able to make informed choices to manage their self care needs.
- Communicate effectively to enable individuals to assess their needs, and develop and gain confidence to self care.
- Support and enable individuals to access appropriate information to manage their self care needs.
- Support and enable individuals to develop skills in self care.
- Support and enable individuals to use technology to support self care.
- Advise individuals how to access support networks and participate in the planning, development and evaluation of services.
- Support and enable risk management and risk taking to maximise independence and choice.

The principles are described in terms of competence, the context in which it lies, the expected behaviours and underpinning knowledge.

Health Foundation: Self management support resource centre

This resource centre is full of information and practical resources that can be adopted and adapted locally to help services and health professionals to develop their own self management support programmes.
Chosen sites have been working in pairs to focus on one of four clinical areas; COPD, Diabetes, Depression and MSK. Case studies can also be found including one from Calderdale and Huddersfield NHS Foundation Trust.

Self care library

The self care library has been designed for use by patients/users and healthcare professionals who deal with long term conditions. The library uses both evidence base and contains information on efficiency, safety and cost.
http://selfcare-library.info

CONDITION SPECIFIC – WITH LINKS TO
PERSONAL CARE PLANNING

Older People
The National Service Framework for older people sets out eight standards that cover the full range of care older people might need. The standards embody fundamental principles ensuring care is based on clinical need not age, and that services treat older people as individuals promoting their quality of life, independence, dignity and their right to make choices about their own care. 
http://www.nhs.uk/NHSEngland/NSF/Pages/Olderpeople.aspx

Multiple Sclerosis
Engaging people with MS in decision-making
People are being encouraged to be partners in medical decision-making and MS is a paradigmatic condition for a shared decision-making approach. As new MS treatment options emerge, patients' involvement in treatment decisions becomes increasingly important. Well informed patients may also be better able to recognise and communicate side-effects. A personal care plan template has been developed specifically for people with MS.
http://www.mstrust.org.uk/professionals/information/wayahead/articles/14042010_03.jsp

Epilepsy
A new Approach to Disease Management for the 21st Century encourages people to work in partnership with health care professionals to manage their condition.

Motor Neurone Disease
Living with MND: Personal care and care support
Changing levels of mobility and independence mean many people need help with personal care, including washing, dressing, and using the toilet. People want to preserve their dignity as far as possible, whilst at the same time accepting practical help.
http://www.healthtalkonline.org/nerves_and_brain/motorneuropathydisease/Topic/3441

Diabetes UK
In the context of Year of Care, care planning is also a means to an end. The care planning consultation identifies what each individual needs to support them to self care effectively. Care planning will also be the essential portal to access many personal care opportunities such as individual budgets.
http://www.diabetes.org.uk/
http://www.diabetes.org.uk/Professionals/Service-improvement-Year-of-Care/The-Year-of-Care-concept/Year-of-Care---care-planning

Emphysema Foundation
The National Emphysema Foundation is currently developing an on line personal health diary and has various exercises and activities for self management.
http://www.emphysemafoundation.org

MEDICINES MANAGEMENT

Medicines management – pharmacy input to compliance
National Prescribing Centre has produced High Level Principles in terms of making local decisions about medicines which also references the input of the individual.
http://www.npc.nhs.uk/patients_medicines
http://www.npc.nhs.uk/local_decision_making/guiding_principles.php

New Medicines Service
This service is aimed at helping individuals adhere to their medicines by offering structured support after discharge from hospital on a new medicine.
http://www.psn.org.uk/pages/nms.html#future

TELEHEALTH AS PART OF THE SHARED DECISION MAKING APPROACH

Kings Fund resources on telehealth and telecare
Telehealth and telecare have the potential to improve the quality of patient care and individual's input to their care. The Kings Fund analysis of the evidence on whether telehealth can be a cost-effective alternative to usual care. Resources include: Perspectives on telehealth and telecare: Learning from the 12 Whole System Demonstrator Action Network (WSDAN) sites; Making a reality of telehealth: Lessons from the Whole System Demonstrator programme.
http://www.kingsfund.org.uk/topics/technology_and_telecare/index.html

E-consultations:
Clinicians share their experiences of using technology and how they have changed their ways of working - what has worked well, what they have learned and tips for others that have resulted in greater efficiency for their organisations and individuals have benefit in care closer to home, reducing emergency admissions, reducing cost and improving access and communication regarding their care.
http://www.yorksandhumber.nhs.uk/what_we_do/improving_patient_care_and_service_quality/informing_decisions_improving_care_/econsultations/#
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**Practices:**

- **Marsh Surgery**, Huddersfield
- **Phoenix Medical Centre**, Bradford
- **Horton Park Medical Centre**, Woodroyd
- **Greenway Medical Practice**, Cleckheaton

Design work by [www.candoocreative.com](http://www.candoocreative.com)

**Yorkshire and the Humber**

2012
From 3 October 2011 NHS North East, NHS North West, Yorkshire and the Humber - the three strategic health authorities in the North Of England - were placed under a single management framework and work together as **NHS North of England**