



Information Prescriptions - National Conference

The right information at the right time

Conference report

March 2008

working with you

to improve social results

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1. Introduction

This conference was held on 19 March 2008 in London. It brought together various organisations involved in piloting 'information prescriptions' over the last year together with those who were interested in hearing more about the concept and experience with implementing it as part of health and social care practice. It provided an opportunity to:

- Present a vision of information prescriptions and the tangible benefits of mainstream implementation drawing on the evaluation conclusions;
- Share the experiences of the twenty pilot sites who have piloted the development and use of information prescriptions over the last year;
- Present the findings of the evaluation of the pilot programme carried out by an independent consortium;
- Explore the different models for delivering information prescriptions;
- Identify the national initiatives which will support national implementation of information in health and social care;
- Provide participants with an opportunity to consider what information prescriptions will mean for their organisations and to influence the direction of future national support work for the national implementation of information prescriptions.

The format of the conference included a number of presentations followed by question and answer sessions with a panel of speakers. These were preceded by exploratory round-table discussions to allow participants an opportunity to reflect on what they had seen and heard and to formulate questions for the panel. Participants were also shown extracts from specially filmed interviews with a range of people from the pilot sites involved in developing and prescribing information prescriptions. Some of the filmed interviews were with patients and carers who received information prescriptions and explored the perceived value and benefit gained from them.

Over lunchtime participants were given an extended networking session where they were able to make contact with individual pilot sites, national charities involved in information prescription work and consortium members who undertook the evaluation review.

The conference was chaired by David Colin Thome, National Director for Primary Care assisted by the Office for Public Management. He also delivered the opening speech intended to be delivered by Ann Keen MP, Parliamentary Under Secretary of State for Health Services, who unfortunately was unable to attend.

All conference participants were provided with a delegate pack of information materials including copies of the presentation slides, a summary evaluation report from the review consortium, a DVD of all the interviews on pilot site experiences and a summary flyer for an online resource about information prescriptions.

This short report on the conference has been prepared mainly to capture the points raised in the question and answer sessions for the benefit of further development work on the national implementation plan. It also provides unedited feedback from the round-table discussions to help the information prescriptions team with further work on national implementation. The report or extracts from it might be useful to use on the information prescriptions website or selected extracts as part of the online resource.

2. The lessons from the pilot programme

Most of the morning sessions of the conference were focused upon the lessons of the pilot programme. Presentations were made by:

- John Cain, Project Manager and Policy Lead on information Prescriptions at Department of Health
- Kai Rudat (OPM) and Richard Glendinning (GfK/NOP) for the evaluation consortium team

The speakers were joined by Ian Maidment, also from the DH IP team, and three people drawn from the pilot sites:

- Geraldine Strathdee, Trust Director of Clinical Services/ACT Consultant, Oxleas Foundation NHS Trust
- Nicola Kingston, Hammersmith and Fulham PCT and Diabetes UK, Asthma UK and Arthritis Care
- Sue Nicholson, Information Prescription Coordinator, Suffolk County Council

A record of the questions and answers in the panel discussion session is provided below. We have also listed all the unanswered questions that were generated in the round-table discussions.

Question and comments with responses from the panel

Question 1: It appeared that some information prescriptions were only issued to users and not to carers as well. Why was this?

Answers:

- There were sometimes legitimate reasons why this happened. It depended where on the care pathway prescriptions were issued and who was involved at that stage. There was some targeted provision for both users/patients and their carers getting comparable information or sometimes bespoke prescriptions.
- There were sometimes to barriers to access to information in how the prescriber interpreted what the user or carer would need access to – e.g. computer access and literacy access to a care line service. This sometimes meant GPs did not always issue the prescription.
- Efforts were made in some sites (Oxleas NHS Foundation Trust) to address the complexities of needs of the user groups and the need to issue prescriptions in a variety of formats not just paper-based ones. It has been important in this site to transform the whole trust staff intranet to ensure ready and easy access to a full range of information that can go into prescriptions.
- In the Suffolk site they were aiming to support the capacity of older people to access information through the library service. It was also important to signpost people back

to the professionals if they needed specific advice on particular matters. They also needed to be very conscious of those with very specific needs such as people with learning disabilities and what support was required to meet these appropriately.

Question 2: GPs have been difficult to engage issuing information prescriptions because of the costs in terms of time and resources.

Answers:

- There is an issue of culture with regard to the kinds of pressures faced by those such as GPs. It was important to identify and encourage GPs and other professionals who can act as champions and role models for others. Efforts are also being made in the education and training of clinicians as part of self care skills to focus on information provision as part of that.
- Part of the role of commissioning is look at priorities across a health patch including information provision as part of the provision of care. The answer to getting GPs to take information provision more seriously may not necessarily be about proving incentives through the Quality Outcomes Framework (QOF).

Question 3: Was there any evidence from the pilot evaluation that the provision of information prescriptions improves health outcomes for patients?

Answers:

- There have been a number of literature reviews of the impact of improved information provisions which shows the positive effects on health outcomes. However the impact of this was something that was usually more apparent in the longer term. Survey feedback as part of the evaluation picked up comments from users and carers about impact and benefits but it was not really systematically asking about health outcomes in the shorter term.
- This part of longitudinal data was not specifically designed into the evaluation methodology. At this stage we cannot tell the full impact of the impact on health outcomes. This might be something that a longer term research might be able to review.
- One of the things that work on health gain was trying to achieve was how to identify patient defined outcome measures. For people with long term medical conditions this might include the capacity to have better control over their lives.
- It is possible in the case of mental health patients to identify such things as a reduction in the incidence of relapse or hospital admissions or the extent to which specific medication empowers them to control their lives more fully. These issues were important in giving staff confidence in providing information to patients. It is possible to measure the level of staff confidence in using this information.
- Although it is still very much preliminary findings at an early stage, the evidence from case studies of those given information prescriptions (in Suffolk) is that it does appear to contribute to health and well being of patients.

Question 4: How can complimentary therapies be incorporated into information prescriptions?

Answers:

- What the analysis of pilot site experience has shown is that there is diverse range of information about different types of services and types of support is what patients/users and carers want to see in information prescriptions. It is important that information prescriptions shifts the balance of power towards the user or carer and that they include whatever it is that they feel they want information on.
- On bio-medical grounds the evidence on the efficacy of a number of complimentary therapies are less effective. Therefore if there is a desire to ensure that validated information is provided on effective interventions that would need to be taken account of in what is included in the information prescription.

Question 5: What have you been doing to ensure that organisation like our own (British Association of Dentistry) are involved in signposting to accurate and appropriate information?

Answers:

- A number of things have been done to quality assure information that is included in information prescriptions including working with a variety of charities, voluntary sector and professional organisations. NHS Choices has been quality assuring the information it provides nationally. In the longer term the information accreditation scheme will be designed to bring all local and national information up to the required standard.
- The library service in Suffolk has been helping users receiving prescriptions not just to access information but to structure it in away that is most useful to them. Individuals can be referred on to particular specialists such as those on medical information who can help with more specific and detailed queries.

Question 6: How do you ensure equity of access to information for different users with the same condition and across different long term conditions? And how will this be evaluated?

Answers:

- Part of the reason for encouraging access to standardised quality assured information is so that all can have access to the same information. However the real power of information prescriptions is to combine this with relevant local information. It is important that organisations work in partnership to share relevant information across different areas to help contribute to improved consistency of information provisions across different patches. There are of course a number of challenges in respect of ensuring consistency of information given the diverse nature of the health and social care system.

Question 7: How do you prevent duplication of effort in work on information prescriptions? What scope is there for translation of information prescriptions into other languages?

Answers:

- This is reflected in the coverage provided in the summary report in the evaluation of information prescriptions.
- Some sites such as the Isle of Wight pilot have managed to developed easy to use website through an open portal that allows access to comprehensive local information.

Question 8: Given that benefits has been a key part of relevant information that might be included in information prescriptions what involvement has there been of the Department of Work and Pensions in the piloting phase of the programme?

Answers:

- The Department of Work and Pensions has been involved in one of the information prescriptions working group. A crucial part of ensuring consistency of information locally was getting access to standardised information nationally.
- A number of the sites (Suffolk and Oxleas) have worked with DWP people locally as well.

Question 9: Can carers be given information prescriptions in their own right?

Answers:

- In the Suffolk pilot site they have been issuing prescriptions to carers in their own right. If there is a benefit from their having a separate prescription they get one or if it is appropriate for them to be copied into a prescription of the person they are caring for that happens as well.
- Evidence from the survey of carers as part of the evaluation indicates that where they are provided with information prescriptions it helps carers feel empowered. It increases their capacity to cope with stress better and to support the person they are caring for.

Other unanswered questions:

- It is all very well libraries 'printing off' information prescriptions – it is not so easy perhaps for people living with a disability or their carer to get to the library to get it!
- Implementation – would a trust attempt to introduce IPs across the whole range of patients and conditions or work only with specific groups?
- Databases of information – how could they capture local information; what clinical governance decisions should be taken about information providers who will be sign-posted?
- What are the costs? [How will £84m be distributed? When?]
 - Training

- Resources
- Technology
- We have concerns around the levels of information to be provided pre-diagnosis. Would you care to comment?
- Are information prescriptions for the “worried well”, middle class? How can we best provide the information to the disengaged?
- EU Information Strategy RE medicines – will this be taken into account?
- Can voluntary groups “prescribe”? Lots interested, active and knowledgeable.
- GPs – do they need to engage with IPs... or not?!
- Resources – time/production of materials. How about some research to show the cost effectiveness of information prescription vs. drug prescription / and information prescription improving outcome of drug prescription i.e. improving the management of the condition. (*see answer on health outcomes*)
- Where will the money come from? Will it be ring-fenced?
- Can some information prescriptions be nationally produced? For rare or complex conditions?
- Is the DH also including their health literacy teams in the development of IP?
- Where are the resources?
- Are there any national standards or national audit?
- How will it link across health and social care?
- How inclusive will this project be?
- Did you explore why some issuers did not offer IPs to all users? Was this a further discrimination?
- Will localisation lead to inconsistency in information and/or duplication with national database?
- What about costs?
 - IT hardware
 - Languages
 - Formats (learning disability, visual impairment)
 - Time
- How can PCTs and GPs be incentivised to deliver info prescriptions?
- Are there any more details available about the national roll out?
- What evidence can you give with regards to getting GPs involved?
- Are those who commission services supporting this?
- What format could be adopted that would be most accessible? Is a stage format solution possible? Is print the best media – given the amount of information required?

- What central help might be available to encourage GPs to participate and take on giving IPs as part of their core role? GPs are often the first point of contact and are trusted as an information source.
- Is there any learning yet (or is it planned) about reduced demand due to improved self care (through better knowledge) that would allow professionals – particularly in primary care – to accommodate giving IPs and managing that workload without creating additional capacity?
- Is there any learning about how and where resource shifts might take place to pay for the additional costs generated by issuing IPs and supporting people to use IPs where there is no new money to pay for this initiative?
- GP practices need to become resource centres. Public need to be educated about different ways of using primary care, e.g. telephone consultations.
- GPs are often first point of contact – how can they be brought on board?
- CSCI finding Oct 2007 re local authorities – any connection?
- IT packages – any information on what to look for?
- Do you think the methodology used for evaluation was fair in terms of disadvantaged groups?
- People with long term conditions like to try alternative therapies – it may be their only relief – when is this going to be subsidised? Disadvantaged are unable to access due to finance.
- How do you engage with GPs – will there be carrots/sticks?
- Presentations frequently mentioned GPs, but what has been done within the pilot projects with regard to acute/secondary/tertiary care? How will IP work in these sectors?
- Inter library referrals (e.g. public use of enquiries to NHS libraries, as insufficient) will need lubrication in many places. What mechanisms/incentives/safeguards can be introduced?

Comments on the evaluation report findings:

- Concern about how to engage GPs.
- Concerned about giving information before a diagnosis.
- Concerned that IPs widen health inequalities.
- For the more personalised IP services – more support required. How will this be resourced?
- How do we ensure the same/good quality information is available across the country
- Is there an expectation all health professionals should be issuing IPs – surely use information experts to provide/support.
- CSCI – mystery shopper, Oct 2007. Why not cross reference lessons?
- “Everyone with a LTC” – remember those doing “self care” and inverting triangle – wider dissemination? Public Health.

- How and when are you going to evaluate the “benefits” to patients?
- Methodology used may have precluded the disadvantaged groups from communicating findings because it was either by paper questionnaire or by catching them for a telephone interview.
- Carers are being seen as an extension of the service user. Carers should not be being “given sight” of a service user prescription they should be being prescribed to in their own right as their needs are *very* different and they should be being made aware of their rights.
- Equality and inclusivity - there doesn't appear to have been much discussion/evidence of literacy and impact for those service users.
- When completing information prescriptions, it is hugely important to include an email address as well as a telephone number, so individuals without speech can access services using their preferred (only) method.
- How disappointing it is to see much little value put on the needs of carers when 6.5 million informal carers save the government £57 million per year!
- The panel member from Suffolk Council said information prescriptions had been given to carers often on the same prescription as person they caring for. They must have a separate prescription in their own right, as have different needs.
- Highlight drop-in session with GPs. Drop in sessions run by secondary mental health service.

3. National initiatives to support local implementation

The afternoon of the conference programme was largely given over to exploring the issues in respect of implementation of information prescriptions across all areas of health and social care. As an introduction to this session there were three presentations given by:

- John Cain, Department of Health – *Implementation and related national policy initiatives*
- Jonathan Carr-Brown, NHS Choices – *The role of NHS Choices*
- Angela Hawley, Department of Health – *Care Planning and Self-Care national policy*

After hearing from each speaker another opportunity was given for round-table reflection and discussion on the theme of national initiatives to formulate any questions and to capture specific observations about what would best help support national roll-out.

The speakers were joined by a second person from NHS Choices who then provided a panel to respond to questions from the conference floor.

Question and comments with responses from the panel

Question 1: In respect of the localisation issue, providing localised NHS Choices – When does such localisation start? How do we get localised information in the system? And what implications might this then have for updating this information?

Answer:

This would happen through NHS Choices. The time frame for local services is not known yet. The pilots for this are running now. There are some decisions that still need to be made and it will not be introduced much before October. However, you will run the local services not NHS Choices. If you need a limited service you can control the content at any time and send updates to NHS Choices. NHS Choices do not want to control the localised content. This is something we simply do not have the resources to do.

Question 2: How reliable are resources? Are they translatable into other languages?

Answer:

Languages are incredible costly because we have enormous amounts of text. Translating things into different languages presents significant difficulties for NHS Choices. But if you are able feel translate materiel yourself NHS Choices could include the material on the site.

Question 3: As far as evaluation of projects is concerned and keeping records of what has been prescribed how can we document what has been prescribed? How can we store the information? Are there any guidelines which are published?

Answer:

The online resource will present a number of good practice examples from the pilots about how projects were evaluated, and prescribing was recorded, although the number of pilots which successfully developed electronic approaches to recording was limited.

Question 4: As far as the continuation of IP pilots, the long-term PCT framework – How will people be motivated to continue or even start information prescriptions?

Answers:

- The White Paper will highlight IP as one priority. As part of the commissioning process priorities are looked at again. Primary Care and Community Care Strategies are high priorities but are still bound to local organisations which will realise them.
- Long term conditions will be key topic in the coming years. Local NHS services have to give options for patients.

Question 5: Can we clarify the term ‘information prescription’ please? Outside of this room, it’s not widely known yet.

Answer:

We have to look at the communication strategy. Communication is one of the major pushes. It’s essential to direct people to NHS Choices.

Question 6: As far as communication about NHS Choices is concerned not much is known currently. What will be done to address this?

Answer:

NHS Choices will be a part of the national support available to Pilots to help local areas implement information prescriptions. The development of NHS Choices is at a relatively early point, but as soon as information about how it will work is available, there will be a much wider communication of how NHS Choices will contribute.

Question 7: Why do we have extension of work in the current pilot sites when NHS Choices is expected to take over now? It was such hard work setting all this up locally and I’m sure that it will upset the communities involved in all of this. When there was an expectation of using NHS Choices why weren’t we consulted earlier? Shouldn’t we have been consulted from day 1?

Answer:

- NHS Choices is only a small part of the package of support which will be made available. Some pilots have developed excellent information systems, and we

encourage sites to build upon this. They don't have to give them up. We need platforms to combine services and information. Individual sites will need to look after their own information content. NHS Choices is a great interface if you don't have any yourselves, and therefore will be useful for sites beginning the process of local implementation. Otherwise you can continue to enrich your existing information systems. We are now at a critical point. We are now looking at how to get people involved. We are more than happy to learn about experiences from pilots. We need to keep the pilots that have established information prescriptions going forward, and continue learning from them.

- We don't want to give the impression that NHS Choices is the only system for accessing relevant information for prescriptions but we need to take the opportunity to gather information from pilot sites and offer wider access to this information. We are working on making the NHS Choices website better. Let's start working together to make these improvements.

Question 8: What counts as an information prescription? What constitutes it? Is self-prescribing of information also included in what can be termed an information prescription?

Answer:

The pilot programme was deliberately set up to give local sites the power to develop IPs in a way they felt would work with local users and care settings. This led to a diversity of practice, including self prescribing. IPs are about a whole approach, including how information is given, and how users are cared for, rather than a single process. We regard self prescribing as a form of prescribing, but are aware that when people require more support this should be made available.

Question 9: How far has work with Museum, Libraries and Archive Council in engaging librarians?

Answer:

We are launching a pilot with the MLA at the moment.

Other unanswered questions:

- Who owns IP within a PCT? Is it commissioning? Is it the providers? It is someone else?
- Is a patient with multiple long term conditions expected to get multiple IPs? Or does one patient get one IP?
- Will we be able to personalise care plans?
- Is the recommendation to create new role to assess and create IPs?
- Angela said there's increased acceptance of responsibility-taking by people but this manifestly isn't the case (people not modifying diet, taking exercise etc. – just taking

medication as the easier step). Several LTAs are preventable, but people not doing this wholesale – as evidenced by the projected increases.

- Interim report budgets mentioned lack of financial support – organisations can't be expected to do such a lot of work with no additional resources. The perception is that DoH issues edicts but doesn't sufficiently support these initiatives.
- What is actually happening about professional education as, we seem to be, starting at a low level i.e. training doctors curriculum doesn't include information/issues/seeking?
- Answer to the translations issue was weak. At present trusts up and down the country are reinventing the wheel whilst being strapped for cash. HCIS produces material for Scotland, for local customising. Why cannot NHS England do the same? I asked this question at a conference two years ago!
- Can we hear now how and where Suffolk got the funding from for the next three years?
- Are the NHS Choices saying that Local Trusts/PCTs will not need to put in their own systems to implement IP.
- Information accreditation is a process-based standard. It does not assume consistency of quality in information.
- Cut and paste information from NHS Choices to translate into community languages.
- Evaluation and guidelines record impact on the service user – prescribe a resource (book/DVD/cassette etc.) – change behaviour.
- Who do we contact at NHS Choices to work on local initiatives?
- Please email to delegates – questions and answers and contact people
- Could rating of information-giving skills be part of rating your local services on NHS Choices?
- As much of the information will be relevant to carers and it is a great opportunity to get this, and more, information to carers, shouldn't carers be included in the national campaign to make them aware that there is information out there?
- How will you incorporate parents and carers in development of the scheme, particularly those of disabled children who were not largely represented in the pilot phase?
- Closer working with health information professionals – librarians in public and NHS libraries.
- When did someone know that NHS Choices involvement in IPs was coming?
- Why did we bother with pilots of Choices is going to provide services anyway?
- Who will be responsible for keeping information up to date on Choices? Currently we are not feeling confident.
- How do we approach our local communities after our IP pilots and tell them that NHS Choices wants to 'take over'?

- Another site/directory to confuse people as to who/where they go to for information – how will you stop this happening?
- How is the NHS Choices information quality assessed at present? Wasn't answered.

What else needs to be considered for national implementation

- Do not rely too greatly on web accessed information.
- Need to consider privacy issues if we are using libraries as a means of accessing computer points
- The work hasn't considered the impact of different information-seeking behaviours, a different issue from cognitive capacities. Research indicates broadly three, but people can move in and out of them at various stages, i.e. active information seeker, selective seeker (screens cut uncomfortable shift), information avoidant. This has implications for tailoring and staging the information. Will send references to Richard Glendinning.
- Voluntary sector involvement was said to be vital. Will this be funded nationally/locally?
- What safeguards will be put in place when information gathering on recommended internet sites (e.g. BBC, Prostate Society) you don't go on to access inappropriate sites. Will NHS Choices recommend sites (it will need to confirm its name!).
- Funding issues – Suffolk's success with funding for the next three years should go in the online resource – how they did it?
- Concern over cost of information – some charities etc currently provide free information – if this has to be accredited through an expensive system there will then be a charge for the information to users and info providers.
- How is the NHS Choices going to be moderated – social network is particular? Does NHS Choices meet the Information Accreditation Scheme draft standards – around translation for instance?
- Could there be a forum on the NHS Choices website itself for feedback about NHS Choices – highlighting missing information or inaccurate information?
- How will partnerships with voluntary sector organisations be developed so that their contribution is valued.
- Work with the patient information specialists. Information giving is a skill! Patient information forum.
- What resources will be given to voluntary organisations who provide content/or input information content?
- How will you ensure a rigorous process is in place for keeping content up to date.
- How are rare conditions to be catered for?
- Some health problems, e.g. neurological conditions are normally diagnosed and treated (initially at least) by specialist NHS staff and services are provided covering several PCTs. Should one PCT take lead? How can this be enforced?

- NHS Choices has to concentrate on the 'big' health problems and long term conditions. How can information about rare conditions be incorporated, say, where the prevalence is 1 in 1000 or 1 in 100000.
- Would like to see health and social care professionals recording information prescriptions given against total number of consultations.
- There are many concerns about providing information before a formal diagnosis, particularly by a GP. They may suspect a certain health problem, but they may be wrong – which is why we have specialists. This may add unnecessarily to worry, decision-making etc. Approximately 30% of all outpatient new referrals have a psychological/somatic cause and not a physical cause. This includes 'setecues', TIAs, etc.
- What consideration is given to relatives/carers, when their loved one is diagnosed with a health problem, e.g. MND, but is in denial? Doesn't want to know about symptoms, progression, prognosis, etc. In theory, the clinician cannot provide an information prescription to a relative and may even be denied that opportunity by the patient.
- You tube style ratings?
- Not sure whether links to 'My Healthspace' are envisaged.
- PCT localisation is a great idea – it needs to link up to map of medicine.
- Need to move away from N3 based initiatives.
- Alternatives to GP take-up initiatives could include training professionals around information prescriptions, i.e. proactive culture change.
- There seem to be weak and diffuse incentives regarding implementation in various areas. How can you enforce this and make sure of compliance?
- Evidence base for QoL outcomes/healthcare benefit outcomes.
- Raising national awareness
- Funding / cash strapped PCOs with too many initiatives to fund.
- NHS Choices:
 - When are they developing the SOCIAL CARE input (esp. benefits!)
 - Who's funding them?
 - How are they getting involved with voluntary sector? Who's funding voluntary sector input?
- Signposting to voluntary sector means extra workload for voluntary sector – How are they being supported?
- Evaluate input/support for patients with medicines, self-care, public health information.
- What is going to be the national driver that will ensure this process is provided throughout England?
- NHS Choices access available in every community pharmacy.
- Self care and LTC including repeat dispensing is provided through community pharmacy. IP provision should be alongside, as part of the service. Discussions with PSNC?

- Where is the money for national implementation?
- Why purchase/commission locally if NHS Choices is planning national and local information delivery?
- It is important that NHS Choices and IPs are not marketed to the public in a way that will confuse people, otherwise the public will be turned off using the system.
- There is a need for IPs to cross over to NHS Choices information to capture valuable information about long term conditions.
- Consultation RE NHS Choices with the public – publish this?
- Who accredits NHS Choices?
- There still seems to be lots of duplication.
- What about ‘age’ specific information e.g. aimed at adolescents.
- Is target of 2008 (presumably 31st Dec) doable?
- What connections between NHS Choices/NHS Direct and local authority call centres on the range of local services
- The whole process of development of information – not resourced well enough.
- Processes in place in trusts that block information even though it has been validated.
- The professionals who would provide the information were not here today. Are they involved in the development of the information?
- NHS Choices being localised. Good idea but how can there be any quality control? Or lack of duplication. The pilots involved PCTs and local councils and councils working with PCTs. Who is checking that two or more organisations in the same area are not doing the same thing?
- I welcome the culture change from state care from cradle to grave to self care, which is a sea change particularly for clinicians, who need to be needed (that is why they are clinicians). They are used to playing God. One was reported in the BMJ as saying “I will get down off my pedestal when my patients get off their knees”. IP are a level playing field between equal citizens and they are the future for healthcare.
johnkapp@btinternet.com see www.reginaldkapp.org for my papers section 9.

Additional analysis of the current situation for the Department of Health

- Training quality information providers
- People don’t see the difference between advice and information
- Not analysis, but question: How near are we to having a potential electronic directory of information or electronic resources to back up national role out?
- That it maybe a hard concept to get across to a wider audience.
- Information must be consistent and of high quality. The accreditation process must be robust.
- You say that there is shortage of workforce: Why are there no jobs for newly qualified “young” NHS trained workforce? Example

- OT
- Physio
- Speech language
 - Who have fantastic assessment skills – district nurses – need more.
- Is this not targeted at the worried well?
- If there is a change of government will this work continue?
- Will there be a specific budget for IP i.e. no other competition from commissioning?
- NHS Choices is a useful resource following early hiccups
- PCT/GP incentivisation is a critical issue in making this happen – need to work with SHAs on this
- Pity we didn't have a pilot in our SHA, as this would have helped us to grow local champions. Consider geographic spread in future.
- A lot more work needs to be done – will this happen?
- Need to get involved with appropriate stakeholders to develop disease state information and more local info availability
- We need champions in place please.
- NHS Connecting for Health – How delayed is the progress with this initiative, e.g. links with community pharmacies etc. How will this affect info and project progress.
- Uncoordinated and lack of focus.
- Trying to be all things to all people. The case has to be made to PCTs.
- Too much reliance on IT and web.
- No support for face-to-face or telephone (personal) information.
- No clear process for working in partnership with voluntary sector in this. Who pays for it?
- Needs distinction between what information is accessed where, e.g. condition specific, service access etc.
- More confused than when arrived – NHS Choices seems to be central; why purchase locally?
- If local choices is going to be local PCT CED how will this encompass community services information and support, as this was identified by service users as part of the information they received as they wanted this to be holistic?
- We have been developing a pilot site as part of community services/LA. Would NHS Choices still look at doing a local version? This may affect joint funding!
- Initiatives that are all related seem to be running in parallel rather than being integrated – IP/cancer info pathways/NHS Choices. Why can't they all be joined up?
- Accreditation is 'topsy-turvy'. Nothing clear about NHS Choices information being accredited so far. As for voluntary sector accreditation – this is coming far too late. It is also unacceptable to contemplate making voluntary sector organisations pay to be accredited.

Appendix 1 – Programme



Information Prescriptions - National Conference

The right information at the right time

9.45am Registration, refreshments and networking

Chair: David Colin-Thomé, National Director for Primary Care, DH

10.30am Introduction – the policy and vision

Ann Keen MP, Parliamentary Under Secretary of State for health services

10.50am Lessons from the pilot programme

- a) Background to the piloting programme
John Cain, Department of Health
- b) Final report findings
Members of the Consortium

11.50am Round table discussions

12.00pm Piloting panel discussion

- Panel members:
- Department of Health
 - Evaluation Consortium
 - Three pilot representatives

12.30pm Extended lunch period – lunch, exhibition and networking

- Foyer:
- Department of Health: Long term conditions team
 - Department of Health: Information for choice team

Congress Suites:

- NHS Choices

Congress Hall:

- Opportunity to meet the people behind the 20 pilot projects and the evaluation consortium

2.00pm National initiatives to support local implementation

- a) Implementation and related national policy initiatives
John Cain, Department of Health
- b) The Role of NHS Choices
Jonathon Carr-Brown, NHS Choices
- c) Care Planning & Self Care national policy
Angela Hawley, Department of Health

2.40pm Round table discussions

3.00pm Implementation panel discussion

Panel members:

- John Cain, Department of Health
- Jonathon Carr-Brown, NHS Choices
- Angela Hawley, Department of Health

3.30pm Close, refreshments and networking

Appendix 2 – Delegate list

Name	Surname	Title	Site / Organisation
Mags	Allison	Head of Publishing and Libraries	Breast Cancer Care
Chris	Anderson	Experience Architect	Map of Medicine
Gordon	Austin	PALS Manager	Buckinghamshire PCT
Dr Lorenzo	Bacelle	Clinical Lead - Information Prescriptions	South Essex Partnership NHS Foundation Trust
Anna	Baker	Specialist Service Manager	Trent Cardiac Network
Richard	Baldock	Long Term Conditions Project Manager	Ashton, Leigh & Wigan PCT
Heather	Ballard	Service Development Manager	NHS East of England
Graham	Barker	Public Affairs and Policy Manager	The Stroke Association
Sarah	Biggs	GP Advisor	
Radhna	Bisnath	Information Prescription Facilitator	University Hospitals Birmingham NHS Foundation Trust Queen
Jane	Bleach		Kent County Council
Jane	Bolding	Patient Advice and Liaison Service Manager	Brighton & Hove City PCT
Sarah	Bone	Chief Executive	Diabetes Research and Wellness Foundation
Sally	Brearley	Chair	Health Link
Katrina	Brockbank	Service Improvement Facilitator	Salisbury Healthcare NHS Trust
Stephen	Brown	Lead Nurse - Memory Service	Leeds Mental Health Trust
Brenda	Bush	PALS Manager	Papworth Hospital NHS Foundation Trust
Roslyn	Byfield	Patient Information Strategy Implementation Manager	South London and Maudsley NHS Foundation Trust
John	Cain		Department of Health
Ruth	Carlyle	Cancer Information Strategy Manager	Macmillan Cancer Support
Jonathan	Carr-Brown		NHS Choices
Michael	Carter	Editor, Patient Information	NAM
Anne-Marie	Causer	Editor	Diabetes Research and Wellness Foundation
Terry	Cawley		Doncaster PCT

Sheba	Cheung		OPM
Sandy	Clarke	South West Regional Lead	Care Services Improvement Partnership
Liz	Coleman	PALS Manager	Eastern and Coastal Kent PCT
David	Colin-Thomé		Department of Health
Angela	Collett	Helpline Manager	Brain and Spine Foundation
Monica	Cooper	Epilepsy Services Manager	Epilepsy Action
Jane	Cramp		Department of Health
Siobhan	Crathern	HealthSpace Business Analyst	NHS Connecting for Health
Jane	Crawford-White	Community Living Manager	Cambridgeshire PCT
Jamie	Cross	Project officer	Department of Health
Sue	Dale	Principal Pharmacist	North Yorkshire & York PCT
Liz	Darlison	Consultant Nurse	Mesothelioma UK
Selina	Davda	Associate Editor	Haymarket Medical Media
Eileen	Dee	Information Officer	Sussex Rehabilitation Centre
Anna	Devalapalli	Assistant Librarian	West Middlesex University Hospital NHS Trust
Susan	Dicks	Assistant Librarian	Nottingham City PCT
Mary	Dignan	Guide and PALS Manager	Gloucestershire Primary Care NHS Trust
Maurice	Dix		Isle of Wight Council
Paul	Dixon		University fo York
Lynne	Dodson	Lead Macmillan Cancer Nurse	University Hospitals Birmingham NHS Foundation Trust Queen
Andrew	Dowser	Chair	MAA
Pat	Duffy	PALS Manager	West Sussex PCT
Sarah	Dutton	Knowledge Manager	Great Yarmouth and Waveney PCT
Yvonne	Elliott	Curriculum Development Coordinator	Milton Keynes Council Adult Continuing Education
Sasha	Enriques	Information Officer	Contact a Family
Alex	Findlay	Assistant Director	National Diabetes Support Team
Luciana	Forzisi	Retrain Recovery Project Coordinator	Institute of Psychiatry

Karen	Friett	Development Manager	The Lymphoedema Support Network
Kim	Gillberg	Asthma UK	Hammersmith & Fulham PCT, Diabetes UK, Asthma UK and
Brian	Glasser	Patient Information Programme Officer	Royal Free University College Medical School
Richard	Glendinning		GFK/NOP
Roger	Goss	Co-director	Patient Concern
Valerie	Greatorex	Patient Support Secretary	International Glaucoma Association
Debbie	Greening	Performance and Development Officer	Brighton & Hove City Council
Sheelaugh	Greenslade	Patient Information / PALS Officer	Royal Liverpool Children's NHS Trust
Kate	Greenwell		North Tyneside General Hospital and Parkinson's Disease Society
Hilary	Grime		Oxfordshire County Council
Julie	Grimes		NHS Choices
Diane	Gwynne-Smith	Director of Knowledge Management	Social Care Institute for Excellence
Anne	Hall	Senior Librarian	Barking & Dagenham Library Services
Karen	Harris	Centre Manager	South Staffordshire Healthcare NHS Foundation Trust
Anne	Haver		OPM
Sheila	Hawkins	Head of Volunteering (Health and Social Care)	Volunteering England
Angela	Hawley		LTC Team
Ferne	Haxby	Head of Customer Services	West Kent PCT
Susan	Haydon	Support Services Manager	The Migraine Trust
Melanie	Hayes	Project Manager	Kent County Council
Sally	Hernando	Head of Knowledge Management and E-learning	NHS South West
Jane	Hesford	PALS Officer	Darlington PCT
Andrea	Hester	Head of Employment Services	NHS Employers
Elaine	Heywood	Macmillan Councillor and Information Officer	Royal Free NHS Trust
Janis	Hickey	Director and Secretary to the Trustees	British Thyroid Foundation
Alison	Hill		Royal Marsden NHS Foundation Trust
Clare	Hinton	PALS Manager	Darlington PCT

Marie	Hounsome	Outreach Clinical Support Librarian	Surrey and Sussex Healthcare NHS Trust
Wendy	Howard	Medical Liaison Manager	Lymphoma Association
Jill	Hudson	Senior Manager	Cambridgeshire and Peterborough Mental Health Partnership NHS
Eluned	Hughes	Senior Education and Information Officer	Breakthrough Breast Cancer
Jaine	Huntley	Service Development Manager	East Sussex County Council
Susan	Hyde		Heart of England NHS Foundation Trust, Birmingham Heartlands
Anna	Jackson	Information Officer	The Carers Resource
Sarah	James	Clinical Project Co-ordinator	Mount Vernon Cancer Centre
Judy	Jansson	Health Information Manager,	Poole Hospital NHS Foundation Trust
Kate	Jarvis	Health Promotion Manager	Asthma UK
Roisin	Joel	Communications Manager	Social Care Institute for Excellence
Claire	John	Clinical Nurse Specialist	North Middlesex Hospital
Mandy	Johnstone		Hampshire Partnership NHS Trust
Gareth	Jones	NHS Liaison Manager	National Pharmacy Association
Anne	Joshua	Associate Director of Pharmacy	Evelina Children's Hospital, Guys and St Thomas NHS Foundation
Joyce	Judson	Information Officer	Nottinghamshire County Teaching PCT
John	Kapp	Patient Rep	PPIF
Laura	Keightley	Advocacy Services Manager	RNIB
Debbie	Keogh	Eye Care Liaison and information Officer	RNIB and Yorkshire and the Humber Strategic Health Authority
Sue	Kernaghan	Macmillan Library Information Facilitator	Wirral PCT
Anna	Kershaw		Department of Health
Ewan	King		OPM
Nicola	Kingston		Hammersmith & Fulham PCT, Diabetes UK, Asthma UK and
Helen	Kirrane	Health and Policy Campaigns Officer	North Tyneside General Hospital and Parkinson's Disease Society
Harprit	Lally	Commissioning Project Support Officer	Lambeth PCT
Sukhjot	Lally	Centre Information Centre Co-ordinator	Walsall Teaching PCT
John	Larkham	PALS Manager	North Staffordshire Combined Healthcare NHS Trust

Guy	Lavis		Department of Health
Clare	Lavis	Social Inclusion Manager	MLA South East
Anthony	Linklater	Clinical Nurse Specialist	UCLH NHS Foundation Trust
Paula	Lloyd	Associate Director - Patient Experience	Cancer Action Team
Paul	Lloyd		OPM
Elizabeth	Lodge	Partnerships Manager	Cancerbackup
Andrew	Lomax	Project Management Officer	Manchester City Council and Manchester PCT
Michael	MacNeil	IT Consultant	
Helen	M Blackburn	Library Manager	Royal Liverpool Children's NHS Trust
Joanna	M. Zakrzewska	Consultant	Eastman Dental Hospital
Ian	Maidment		Department of Health
Nitin	Makadia	Professional Services Development Manager	Lloyds Pharmacy
Rod	Marshall	Practice Manager	Parkside Medical Centre
Graham	Matthews	Manager. Health Libraries	Rotherham Foundation NHS Trust
Sarah	McHugh	Associate Director	GFK/NOP
Drew	McLaren	Customer Insight Manager	Disability & Carer Services
Lizzie	McLennan	Policy office - health and Social Care	Help the Aged
Fiona	McQuiston		County Durham PCT Macmillan Cancer Information & Support
Jo	Metcalfe	Independent Advisor	Department of Health
Wayne	Middleton	Innovations and Development Manager	Evelina Children's Hospital, Guys and St Thomas NHS Foundation
Jasmine	Miller		OPM
Ralph	Mold		Department of Health
Marie	Montague	Medical Library Operations Manager	Queen Mary University of London
Paddy	Moon		Association of Disabled Professionals
Debra	Moore	Joint Programme Lead and Health Lead	Valuing People Support Team
Kim	Morley	Sapphire Epilepsy Specialist Nurse	Southampton City PCT
Jeremy	Moyse	Development Officer	Swindon Borough Council

Tom	Murphy	PALS Manager	The Walton Centre for Neurology and Neurosurgery NHS Trust
Lyn	Mynott	Chair	Thyroid UK
Edith	Nash	Project Manager	Cambridgeshire and Peterborough Mental Health Partnership NHS
Sue	Nicholson	Information on Prescription Co-ordinator	Suffolk County Council
Bridget	O'Connell	Information Manager	MIND
Alison	Paul	Deputy manager, Library and Knowledge Services	Ashford and St Peters Hospitals NHS Trust
Suzanne	Paylor	Policy Manager	Department of Health
Rowena	Perry	Library Manager	Berkshire Shared Services
Karen	Pilkington	Senior Research Fellow	University of Westminster
Rosalyn	Pitt	Library and Knowledge Services Manager	South Staffordshire Healthcare NHS Foundation Trust
Mark	Platt	Policy Director	Long Term Conditions Alliance
Natasha	Posner	Senior Research Fellow	University of Warwick School of Health & Social Studies
David	Potter	Information Services Manager	Multiple Sclerosis Society
Debra	Powiesnik		South Essex Partnership NHS Foundation Trust
Andrew	Pryde	Public Empowerment Communications Manager	Department of Health
Juliet	Pudney	Commissioning and Change Manager	North Yorkshire County Council
Joanne	Quayle	Information Manager	Endometriosis UK
Nina	Rai		Heart of England NHS Foundation Trust, Birmingham Heartlands
Kismet	Rashid	Project Manager	Office for Disability Issues
Amanda	Reeves	Low Vision Service Manager	The Macular Disease Society
Graham	Reid	IAS Policy Manager	Department of Health
Doreen	Rhodes	Library and Information Services Manager	Sandyford Initiative
Karen	Rix	Clinical Team Leader	Association of Chartered Physios in the Community
Sandra	Rowlands	Support Manager	Merseyside and Cheshire Cancer Network
Margaret	Rowley	Head of Knowledge Management	Worcestershire Acute NHS Trust
Helen	Rowntree	Pathways Lead	Department of Health
Kai	Rudat		OPM

Jenny	Sandham	Senior Customer Insight Manager	Disability and Carers Services
Sharon	Schillerstrom	Care Development Information Manager	Motor Neurone Disease Association
Vicky	Sergaent	Outreach Librarian	Cheshire & Wirral Partnership NHS Foundation Trust
David	Shaer	Complex Needs Service Manager	Oxleas NHS Foundation Trust
Bryony	Shannon	Information and Communications Officer	Sheffield City Council
Rebecca	Sheehy	Senior Project Manager	RNIB and Yorkshire and the Humber Strategic Health Authority
Louise	Sheperd	Manager, Library and Computing Services	University College London
Ann	Skinner	Information Specialist	Quality: MK
Tracey	Slater	Assistant Director	Doncaster PCT
Sarah	Smith	Director	Healthsmith
Peter	Smith		Isle of Wight Council
Hazel	Sommerville	Head Pharmacist	Commission for Social Care Inspection
Anna	Spain	Information Prescription Co-ordinator	Barking & Dagenham PCT
Dan	Spiers	Information Publications Officer	British Lung Foundation
Sharon	Springham	Deputy Head of Library Services	Brighton and Sussex University Hospitals NHS Trust
Nick	Stewart	Support Time and Recovery Worker	South London and Maudsley NHS Foundation Trust
Diana	Still	Patient Advice and Liaison Co-ordinator	Mid Essex PCT
Geraldine	Strathdee	Trust Director of Clinical Services/ACT Consultant	Oxleas NHS Foundation Trust
Glenn	Street	Carers Strategy Development Officer	Manchester City Council
Sandra	Sweeney	Senior Pharmacist	North Yorkshire & York PCT
Nuttan	Tanna	Consultant Pharmacist	North West London Hospitals NHS Trust
Debbie	Taylor	Clinical Quality Improvement Manager	North East London Mental Health NHS Trust
Helen	Terry	Information and Support Services Manager	National Association for Colitis & Cohn's Disease
Kathryn	Topping	Information Officer	Neurosupport
Linda	Towers	PALS Co-ordinator	Sheffield Children's NHS Foundation Trust
Bridget	Turner	Diabetes UK	Hammersmith & Fulham PCT, Diabetes UK, Asthma UK and
Maggie	Udell	Information Officer	The Association for Real Change (ARC)

Sheela	Upadhyaya	Business Manager	British Association of Dermatologists
Vanessa	Vale	Commissioning Manager	Derbyshire County PCT
Beverly	Van Der Molen		Royal Marsden NHS Foundation Trust
Meredith	Vivian	Acting Director, Patient and Public Engagement	Department of Health
Fiona	Walker	Library and Information Services Manager	Sandyford Initiative
Kelly	Wallace-Bates	Macmillan Information & Support Manager	East & North Herts Trust
Heather	Webber	Group Manager	The Stroke Association
Clare	Wener		Department of Health
Simon	Wheeler	Business Development Manager	Redback Design Ltd
Alison	Wheeler	Adult Services Manager	Suffolk County Council
Glenys	Willars	Development Manager	Leicester City Council
Jennifer	Williams	Library Manager	Croydon PCT
Sheila	Williamson	Management Consultant for Information Prescription	Mid Trent Cancer Network, Nottingham University Hospitals
Lyn	Wilson	Patient Information Librarian	University Hospital Coventry and Warwickshire
Linda	Witchell	Governance Manager	Royal Bournemouth & Christchurch Hospital NHS Foundation Trust
Veronica	Wray	Communications Consultant	Insulin Dependent Diabetes Trust (IDDT)
Mary	Wrenn	Cancer Information Co-ordinator	Canceri
Lorraine	Wright		NHS East Midlands SHA
John	Parker	Brain Injury Case Manager	Nottingham University Hospitals
James	Benham	Head of Publishing	Binleys
Deirdre	Doogan	Head of Government Relations	Lloyds Pharmacy
Carl	Evans		LTC Team
Peter	Gill	Senior Information Officer	Alzheimer's Society
Debbie	Goulding		Department of Health
Martyn	Hooper	Executive Chairman	The Pernicious Anaemia Society
Michelle	Jones		Oxfordshire County Council
Kate	Llewelyn	Head of Information Services	Arthritis Care

Clare-Louise	Nicholls	Programme Manager	North Somerset PCT
Michael	Roche	Social Care Information Specialist	Age Concern England
Sarah	Talbot	GP	
Richard	Tiner	Medical Director	ABPI
Richard	Tolson	Service Development Manager	Action for Blind People
Clare	Vollum	Assistant Director of Health Programmes	RNID
Elaine	Wilson	Nurse Director	Mid Trent Cancer Network, Nottingham University Hospitals
Claire	Willis	Information and Publications Manager	RNID