



**Response to  
Professor Sir Mike Richards  
review of the  
Cancer Reform Strategy**

**September 2010**

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# 1. Executive Summary

Professor Sir Mike Richards invited contributions to the review of the Cancer Reform Strategy. Members of Independent Cancer Patients' Voice have discussed the review in detail, and have compiled this response. Our members are in the main breast cancer patients, but are aware of the issues in other cancers, and have aimed to provide a generic cancer patient response.

There was very clear agreement on our priorities- acknowledging the improvements from the Cancer Reform Strategy and recognising the need to add to the pace of these improvements.

**Cancer Networks** provide an excellent vehicle for improving collaboration between research and treatment leading to improved outcomes for patients. This includes communication between specialist and district hospitals, GPs and patients/carers and the provision of high quality, accurate information for patients and carers. Networks need to be properly funded and resourced to achieve their potential value.

**Diagnostic Centres and Public Health style clinics** (well-woman/man and 60+ clinics) could promote earlier diagnosis and self-referral. There is a need to review provision for those with learning difficulties and other disadvantaged groups but we feel their needs are better met through public health. More cancer prevention in health education is needed in schools and colleges.

**Clinical Nurse Specialists** for all tumour groups are essential and their role must be protected and enhanced. There needs to be provision for patients with less common cancers and for those with secondary disease.

**Pathology Services** are under resourced and there is inequity in provision of a quality service in which all patients can be confident. Good pathology is the cornerstone of good treatment.

**Radiotherapy services** also need proper resourcing in order to provide equity – All patients should have the choice of new forms of treatment where this is appropriate and could mean more effective and/or less invasive treatment even if this involves further travel to access such treatment, eg IMRT, IGRT, IORT, CyberknifeRT.

**MDTs** are essential to improve cancer patients' outcomes. Patients are becoming more aware of these and of their function with a resulting increase in confidence regarding decisions about their own treatment. They need to be allocated sufficient time and administrative support.

**Reconfiguration of services** will be needed to ensure provision of some specialised equipment and expertise which cannot be funded in all treatment centres. However, this needs to be after full public consultation and be for genuine patient benefit not to meet political or financial targets and there must be due consideration of all supporting services.

**Patient choice** may not be a priority for many patients but will be a must for some – eg to ensure more expert treatment for a particular tumour type or to enable treatment nearer to

where family is based. Most patients would prefer to be treated at their nearest hospital – as long as this did not reduce the standard/choice of treatment. Most would willingly travel further if this gave a higher potential benefit in terms of service and outcome.

More needs to be done to promote **PPI** in both service improvement/development and research. Patients and carers need to feel a responsibility in their own care and in improving care for future patients – they need to know about opportunities for involvement and that this input is constructive and valued. A good example is the poster produced by the LNR Cancer Research Network and the SWSH CPRG leaflet.

In section 9 we include comments from individual patients, which we consider give a flavour of the issues which are particularly important to them and to others. In our final section we discuss **Key information for informed patient choice**

### **Are there particular priority areas for action which need to be addressed if cancer outcomes are to be improved?**

- Early and correct diagnosis
  - We hear it is still a problem.
- Clinical Nurse Specialist
  - made all the difference to their treatment and outcome.
  - Consistent message from patients
- Cancer Networks
  - Very highly valued
  - Maintained and strengthen
  - PPI integral part of commissioning
  - Funding and resources are needed to provide training and support for lay members
- Centres of excellence
  - Best examples of good patient outcomes - patients treated at specialist centres.
- Multi-disciplinary teams
- Pathology
  - Increasing role for specialist pathology services - new biomarkers - increased stratification
  - Gross underfunding - needs urgent attention.
- Clinical trials – evidence based medicine
  - NHS excellent trials environment
  - Threat from outsourcing and commissioning of services from outside the NHS
- CAT led peer review of cancer services
  - Maintain and include PROMS

### **What opportunities are there for delivering efficiencies or saving money in cancer care?**

- Clinical Nurse Specialists
  - Save money for the NHS and should be protected.
- Earlier Diagnosis
  - Better treatment programme and prognosis and NHS costs.
- Treatment Factors

- Centres of excellence -improve efficiency, remove duplication, save money and improve outcomes
- Complementary Therapies
  - Signpost to accredited centres not provision by NHS.
- Drugs
  - Reduce costs by more selective/stratified-use
- “CANCER DRUGS FUND”
  - Must have evidence based governance and cover treatment
- Data Collection
  - Ultimately save both lives and money.
- Follow-Up
  - Rapid direct specialist access vs “traditional” routine follow-up better for patients
- Supportive and Palliative Care
  - Earlier referral to supportive and palliative care will save money for the NHS and improve patient outcomes.

### **How best can quality and outcomes in cancer care be measured?**

- Patient Reported Outcomes Measures (PROMs) good
  - Patients must be involved in design and evaluation
- Registries & Data Collection
  - National Cancer Intelligence Network is doing fantastic work
  - Central to determining quality and outcomes- maintain and continue to improve
  - Standardise data collection
  - Data on recurrence and treatment

### **What further action is required to improve patients’ experience of treatment and care?**

- Clinical Nurse Specialist
  - Highly valued by cancer patients - crucial to improving patient experience.
  - Expand and protect to prevent de-skilling
- Screening
  - Need a proper, open debate about the benefits/harms of cancer screening and its affordability
- More and Effective Patient Input
  - We like “No decision about me without me”
  - Value the existing cancer networks for PPI
- Improve the language of all who come into contact with patients
  - Medical staff must use simple and sympathetic language in clear and comprehensive English.
- Better Patient information
  - Clear and honest patient information
  - Patient held records
- NICE recommendations and Improving Outcomes Guidelines
  - Measurable Data needed to show improved outcomes of treatment and care.
- Regulation of Private Health Care Providers
  - Subject to the same quality standards as everyone else

- Anecdotal evidence of poor quality provision by private health care providers.
- Increased NHS staffing needed

**Are you aware of examples of good practice in cancer service delivery which could be replicated?**

Patients with many years' experience of NHS. - direct experience and of others

- Substantial evidence of examples of good practice from:
  - Royal Marsden, Frenchay, York, UCLH, Avon Breast Screening, St Georges, Kings College Hospital, Velindre Cardiff, Royal Bournemouth, Leeds, Bath radiotherapy department, NCRI Breast Intergroup, Wales, Leeds, Mount Vernon & Hillingdon, Bristol, Sussex, Islington ELiPSe team), York District Hospital

**What developments in prevention, screening, diagnosis, treatment or after care can be expected which will impact upon the way in which cancer services need to be commissioned or delivered?**

- Use of gadgets
- Biomarkers
- Diagnostic Centres
- Central specialised commissioning
  - Intra-operative radiotherapy, IMRT, IGRT
  - Better data collection and storage
  - Electronic records
  - Biobanks

**Looking at the plans set out in the White Paper and associated consultation documents (to be published shortly), what are the issues and opportunities for delivering cancer services and improved outcomes?**

- Concern about GP consortia led commissioning for cancer.
  - GPs generalists - GPs will not see enough cancer patients
  - GPs may be overly influenced by financial considerations rather than the best interests of patients

**As we develop work to improve cancer outcomes, how can we make sure that we continue to try and tackle inequalities in cancer care?**

- Engage with INFORMED Patient & Public Advocacy Groups
- Ensure that all areas meet a minimum standard of care available over 24hrs.
- Continue to improve language of all in patients contact
- Work with Age UK. and other third sector organisations patient held records
- Commissioning bodies must have proper patient input
- Specialist centres necessary for Less common cancers

Independent Cancer Patients' Voice September 2010

## 2. Introduction & Methodology

This document is a contribution to a review of the Cancer Reform Strategy (CRS) being conducted by Professor Sir Mike Richards following a request from the Secretary of State for Health, Andrew Lansley MP, and the Minister of State for Care Services, Paul Burstow MP. The review aims to ensure that we have the right strategy, subject to the Spending Review, to deliver improved survival rates for cancer.

### *Independent Cancer Patients' Voice*

Independent Cancer Patients' Voice (ICPV) is a patient advocate group independent of established UK cancer charities and aware of the value of medical research to both public health and to the national economy. Our experiences as patient advocates lead us to believe that medical research in the UK needs an independent cancer patients' group, whose strategy is led by patients. Although initially focused on breast cancer, we bring the opinions, views and experience of cancer patients, their family and carers, to the cancer research community– the voice of the patient.

Our aim is to improve existing treatments for every cancer patient and develop new treatments by bringing the patients' voice into clinical research to improve outcomes for all cancer patients. We do this by

1. educating, supporting and mentoring patients so that they can have an equal voice with clinicians and researchers and
2. bringing the patients' voice to clinicians and researchers – i.e. by being patient advocates in clinical research so that this research takes into account the patients' (and carers, relatives etc) viewpoint to improve outcomes (cancer mortality, morbidity, quality of life) for all people affected by cancer (patients, relatives, carers).

We involve patients in clinical research (including clinical trials, working with clinical/academic units, tissue banks etc) putting the patient perspective and helping to improve clinical research. This, we believe, leads to better recruitment to clinical trials and faster improvements in treatments and outcomes for all cancer patients.

To enable patients to do this, we run study days where cancer patients meet academics and clinicians who work in cancer research at their centres of excellence. Our study days aim to raise the patients' level of clinical knowledge of new treatments, latest scientific developments, statistics, basic biology and to help the academics and clinicians understand the patients' perspective. The days also empower patients to speak as equals with the professionals as patient advocates. Our study days have also gained appreciation from clinicians and researchers (eg Peter Barrett-Lee, Velindre Cardiff, Mark Ormstein Barts London) who have found them of great value – they learn as we do –and we are mentioned in the breast clinical studies group review.

We aim to work within the National Cancer Research Institute (NCRI) framework to enable proper monitoring and review of our activity and value. Most of our members are involved in

the design and/or running of at least one clinical trial (naturally they are not themselves participants as patients in the trial). We work as advocates at a strategic level (at the NCRI) with clinicians and clinical researchers in order to improve clinical research and outcomes for all cancer patients. For example, we have

- Re-written patient information leaflets, influenced trial design to make it more likely patients will enrol and encouraged patients to join the trials by sharing our own experiences (see appendix 1 for our own leaflet encouraging patients to join trials);
- Changed the views of ethics committees to prevent unnecessary barriers to research (PERSEPHONE consent to translation sub studies granted)
- Influenced MREC over consent to the use of tissue (TACT reversed block on tissue being used for research)
- Supported and continue to work with Breast Cancer Campaign's Tissue Bank's board of management and tissue access committee
- Contributed to other clinical trials including
  - IMPORT HIGH & LOW
  - POETIC
  - iBREAST

## ***Methodology***

Through our active Google group we circulated to our members links to the Government White Paper consultation documents and the request for submissions from Professor Sir Mike Richards for the review of the Cancer Reform Strategy.

Following a preliminary discussion on the Google group, we organised an event in late August 2010. We used the Knowledge Café model to manage the sharing of information and one of our members acted as facilitator to keep the discussion moving. Another member acted as scribe. From this day, a draft document was prepared which also included written contributions from members who couldn't be present. The draft document was circulated and then discussed at a further meeting of our members. This document was distilled from that final discussion and written comments on the draft.

### **3. Are there particular priority areas for action which need to be addressed if cancer outcomes are to be improved?**

There needs to be clarity about what "Improved Outcome" means. Information is needed to try to understand what interventions make a difference to improve outcomes. The baseline for all reconfigurations should be the current outcomes baseline, and a target should be set so that improvement to outcomes can be measured. The outcomes required should be clearly defined at the outset. There also needs to be proper consideration of quality and the configuration of supporting services such as pathology.

#### ***Early and correct diagnosis***

Although a great deal of work has been done on early diagnosis, we hear that it is still a problem. We hear countless tales from patients about delayed and incorrect referral from GPs, people going back again and again before being investigated and then referred on too late for curative treatment.

#### **We suggest a Revival of Well-Woman/Man/50+ Clinics.**

- These are effective as the doctors and nurses are specialised and have more interest and skills.
- Many people are more comfortable using them as they are "not wasting my doctor's time".
- They are cheaper than GPs because they are paid per session and not per patient.
- There should be direct referral to consultant with copy to GP so that there is no delay caused by referral to GP who then refers to hospital.
- They reduce inequality because they increase accessibility to disadvantaged groups reluctant to see GPs

#### ***Clinical Nurse Specialist***

If there is one consistent message from our members and the patients they talk to, it is how a Clinical Nurse Specialist (CNS) made all the difference to their treatment and outcome. For patients, adequate provision of CNSs a priority - they are seen as the key-worker, pathway co-ordinator, family support and main source of readily available expertise, advice and support. Their role must be protected and properly funded - they save the NHS money by avoiding duplication, preventing unnecessary readmissions, properly interfacing with primary care and reducing need for attending clinics. They also save patient and carer increased financial costs as well as reducing anxiety and distress. If their work is diluted by having to undertake non-specialist work this will reduce their specialist skills and wastes the time and money spent by them and the NHS in becoming specialists.

#### **Clinical nurse specialists:**

- enable earlier discharge from hospital,
- facilitate a quick response to problems,
- explain treatments and expected "pathway",

- help to cope with difficult information/emotional feelings and psychosocial care of patient,
- signpost patients to more help.
- recognise the needs of carers,
- run rapid access & triage clinics,
- provide continuity of care and continuity in follow-up clinics.

We recommend examples in breast follow-up at Bristol, Mount Vernon, UCLH, RMH and St Georges. (Section 7)

We consider the clinical nurse specialist to be “THE Patient Advocate” in the multi-disciplinary team and that their skills should be expanded and their role protected to prevent de-skilling and consequent reduction in the patient benefit.

### ***Cancer Networks***

Cancer Networks were established through the NHS Cancer Plan produced in 2000 and reinforced by the Cancer Reform Strategy in 2007.

They have been very effective in increasing collaboration amongst health professionals, researchers and patients which enables improvements in cancer services, treatments, recruitment to trials and improved patient reported outcomes. Networks have ensured more "joined-up" service provision with better co-ordination between primary and secondary care and between specialist and generalist hospitals and the patient's GP. There needs to be increased collaboration between cancer networks and with the NCRN.

- As patients, we value Cancer Networks very highly and would like to see them maintained and strengthened

**Patient and Public Involvement (PPI)** has become a valued part of the process rather than a "tick the box" exercise in Network Site Specific Groups, Cancer Service Partnership Groups and Cancer Research Partnership Groups. Patients' and carers' voices can assist the development of new services as well as adapting current practice to make it more effective and "patient friendly" –

PPI can also reduce NHS costs by saving time of staff and equipment. Cancer patient/ carer experience of cancer care is an important outcome measure. Patients review most patient information literature, including consent and participation in trials leaflets - making these fit the purpose being easily understood/ less complicated whilst ensuring full information is provided. Patients participate in research by sitting on trial management groups in addition to those actually entering trials.

- PPI should be integral part of commissioning and designing of services in all networks.

#### **In order to increase PPI activity,**

- funding and resources are needed to provide training and support for lay members of these groups –
- and to increase the recruitment of interested members of the public in order to reduce the burden on those already involved.

The value of effective PPI has not always been recognised by commissioners and there is inadequate funding to cover costs of involvement.

## ***Centres of excellence***

The best examples of good patient outcomes come from our members treated at specialist centres.

- Centralisation and specialisation is a “must” particularly for less common cancers but also for the big four as increasing stratification leads to smaller patient groups.
- Patients will accept increased travel when necessary to access better/more appropriate treatment by referral to a centre with more expertise in a particular cancer.
- Specialist surgery should be carried out by specialist surgeons with publication of data regarding their practice.
- There must be improved collaboration between centres of excellence and local units.

## ***Multi-disciplinary teams***

We have found that good patient outcomes require multi-disciplinary teams. They are absolutely vital and quite possibly the biggest contributor to improved outcomes of cancer strategy

- All treating hospitals must have MDTs
- MDTs must continue and this means maintaining the administrative support for these teams.
- Our experience of breast cancer suggests that MDTs for secondary cancer should be established in all treating centres as these improve outcomes.
- There may be a place for the presence of a patient advocate.
- A pathologist must be present , as pathology services are vitally important. –

## ***Pathology***

Patients are becoming much more aware of the vital role of pathology in their diagnosis and treatment – and, thus, the likely outcome for them. There is an increasing role for specialist pathology services with new biomarkers and for increased stratification of cancer treatment based on pathology. This will improve outcomes for some whilst preventing ineffective or unnecessary treatment and side effects for others.

There is a gross underfunding of quality and specialist pathology which needs urgent attention. We need to ensure that high quality, safe cancer pathology services can be sustained in the future, given the challenge posed by the national shortage of pathologists.

Meanwhile, a strategy is needed to ensure that the optimum possible service is provided from existing resources. We recognise that some specialist pathology needs to be carried out at specialist centres but other testing should be done on-site to ensure rapid results and proper pathology input at MDTs.

- There is an urgent need to increase the funding/review the quality of pathology services.
- There should be accreditation of all pathology departments (NHS and private) with QA of both equipment and staff.
- There must be a benchmark of quality ie. consistent and accurate reporting.
- The Care Quality Commission should regulate standards of reporting.
- External quality assurance (EQA) should be an audit process, not educational.

We have some questions about suggested changes in pathology services –

- What is meant by “Private Involvement”? – Does this mean NHS pathologists providing a service to the private sector, or the NHS sending work to the private sector?
- How does “private” fit with working with MDTs?
- Who is responsible for QA?

### ***Clinical trials – evidence based medicine***

Patients participating in clinical trials have improved outcomes and the trials will benefit future patients. Patients are becoming more aware of the value of research, which will become a factor in their choice of referral for treatment: a hospital which has established a reputation for quality research will be attractive to potential patients. (for example Royal Marsden, UCLH, Christie, Edinburgh, Leeds, Royal Bournemouth).

The NHS provides an environment for performing clinical research that is the envy of the world, and a unique patient base for medical research - patients, data, samples, trials. This could be threatened by outsourcing and commissioning of services from outside the NHS (- eg when pathology is outsourced, the pathologist is not onsite to attend MDTs and to influence the clinicians treating the patients nor to debate research issues with hospital based researchers.)

We are also concerned about data sharing between different bodies - especially if some are commercial. It should be stipulated in contracts that data obtained from patients & for the benefit of patients, must be shared. We hope that this environment will be maintained.

We hear that the number of clinical trials running in the UK has fallen and also recruitment to trials has dropped and we are concerned about this. We are also concerned about the poor level of investment in radiobiology and radiotherapy research.

We welcome a reduction in bureaucracy regarding applications for Ethical Approval for trials. A similar reduction should be possible in R&D - a national approval with very limited need for local adjustment would greatly reduce the delays in start-up at some centres and reduce the costs involved. The application of the European Directive should be risk stratified for individual studies, eg studies using drugs which have already been in use as compared with studies using new drugs.

- Any commissioning should ensure the continuity of the NHS research base.
- All clinical trial design should include patient input.
- All patients should have the opportunity to enter a clinical trial.
- Every hospital should encourage patients to enter clinical trials.
- Procedures for setting up and running clinical trials should be simplified.
- Trials should be initiated and led by academia and supported by pharma. Increasingly clinical trials are driven by the interests of pharmaceutical companies and not by patient outcomes.
- Increased investment in radiobiology is needed to support faster access to diagnostic imaging and radiotherapy

We include our evidence to the Academy of Medical Sciences review of the regulation and governance of medical research (Appendix 2)

### ***CAT led peer review of cancer services***

Peer Review is an excellent method of assessment of quality of cancer service provision and is effective because the review is carried out by peer professionals who understand both the aims and the difficulties of excellent service provision. It is expensive as it takes professionals away

from their own cancer networks but it is very cost effective and ensures that good practice is recognised and taken back to other networks. Criticism is constructive and made by professionals in same field and can add weight to plans for future development. Patients/consumers are always members of reviewing panel but should also be members of team being reviewed.

There is wide patient support for a shift to more outcome based measures as an effective lever for change.

- Patient input very valuable and should be maintained
- Patient Reported Outcome Measures should form part of peer review assessment.
- Patients should contribute to both the process of review and the shaping of the quality measures.
- The reports should be made more available to share good practice.
- Peer review of pathology, specialist reporting, quality assurance, labs accredited.

## **4. What opportunities are there for delivering efficiencies or saving money in cancer care?**

Following an in depth discussion about the strengths and weaknesses of the NHS, we had two general suggestions for the most effective way to save money and to increase efficiency:

- To remove the internal market and competition in the NHS (and with private health providers) and all the administration it requires, and invest the considerable sum in providers and regulators.
- Should private sector involvement in the NHS be deemed unavoidable, controls should be put in place to ensure that it is rigorously negotiated and monitored (ensuring that none of our money is paid out in profits/excessive pay and bonuses to private health care providers); that it does not have adverse effects on the NHS (e.g. cherry-picking profitable procedures); and that the benefits to patients are greater than those that would be achieved by the NHS with similar levels of resource.

### ***Clinical Nurse Specialists***

We feel very strongly that clinical nurse specialists save money for the NHS and should be protected. We make no apology for the repetition of some of the points on clinical nurse specialists in this section. They are vital for enhanced patient experience. They are cost effective for both patient and the NHS. Clinical Nurse Specialists save money by:

- enabling earlier discharge from hospital,
- facilitating a quick response to problems,
- explaining treatments and expected “pathway”,
- helping to cope with difficult information/emotional feelings and psychosocial care of patient,
- signpost patients to more help
- recognising the needs of carers.
- running rapid access & triage clinics,
- providing continuity of care and continuity in follow-up clinics

### ***Earlier Diagnosis***

Earlier diagnosis ensures a better treatment programme and prognosis and therefore reduces the cost to the NHS.

- Introduce some form of cost neutral incentive/penalty for GPs to diagnose cancer at an earlier stage,
- Public awareness of signs and symptoms,
- Better and more targeted screening,
- Public Health improvements –
- Increased role for well-woman/man clinics,
- Increased numbers of diagnostic centres,
- More testing of awareness initiatives to support effective public education.
- Ensure that all GP consortia have GPs with specialist cancer knowledge

In addition, there needs to be an open and frank discussion, based on unbiased peer-reviewed evidence, of the harms/benefits and affordability of screening. This is a question for NICE, patients and public as well as the NHS.

### ***Treatment Factors***

We believe that effective deployment of “Hub and Spoke” model for all cancer services will improve efficiency, remove duplication, save money and improve outcomes for cancer patients. This means regional (or national) centres of excellence providing very specialist skills and equipment, including pathology, working with local cancer providers for more routine investigations and treatments – including treatments at home if safe. Reconfiguration of some services will be needed but will need proper consideration of quality and the configuration of supporting services such as pathology. We are unsure how this could be achieved through GP commissioning and feel that all cancer services should be centrally commissioned.

### ***Complementary Therapies***

There should be good signposting to accredited centres for complementary therapies, eg Maggie Centres, rather than provision by NHS. These centres should undertake research/studies to assess the benefit of their therapies and these should be published and peer reviewed. They should contain objectively measurable end-points as well as patient reported outcomes.

### ***Drugs***

More research is needed to define which drugs are effective for which tumours and the length of treatment needed – especially the development of biomarkers to stratify patient populations. This would reduce costs by restricting use to those patients for whom the drug is effective. It would also mean that patients are not subject to side effects of a treatment which is unlikely to have any benefit.

- More concurrent treatment should be given where possible – including entry to trials.
- Better control over drug costs – more effective negotiation with pharma on this as well as collaboration in research.
- The “CANCER FUND” needs governance, should be evidence based and must cover treatment costs as well as the cost of the drugs.
- “NICE” should take more account of specialist evidence in its assessments, eg a member representing the views of 30+ experts in a relevant Clinical Studies Group should carry more weight.. This will make the NICE assessment process better informed and reduce the costs associated with appeals.

### ***Data Collection***

Electronic records are a “must” but patient-held records (as per the ante-natal Shared care card) would also improve transfer between hospital, GP and patient of up-to-date information about investigations and treatment, and keep the patient/family in the loop. Ultimately this will save both lives and money.

## ***Follow-Up***

We feel that if rapid and direct access to a specialist is available then the “traditional” pattern of regular routine follow-up is not necessary and will save money for the NHS (We have assumed during this discussion that follow-up for cancer patients will be provided by a specialist cancer centre).

- The expected pathway, including follow-up, should be discussed with the patient and carer from the start of treatment with reassurance that very easy re-entry to the system will be available if needed and information on when to act.
- There are several models for follow-up which reduce the numbers continuing to attend clinics for many years. (Full information and discussion will be needed for follow-up of patients participating in clinical trials.)

### **Open access follow-up**

- Direct access to specialist within a week, ie **not** through GP,
- Piloting with range of tumour groups needed,
- There is wide patient support for more effective use of resources here as long as there is confidence in rapid access,
- Nurse led follow-up at annual mammogram successful (radiographer led in Cardiff)
- We have more on good examples of successful follow-up (Section 7)

## ***Supportive and Palliative Care***

We feel strongly that earlier referral to supportive and palliative care will save money for the NHS and improve patient outcomes.

- Earlier referral for symptom control, would also make easier referral for end-of-life care when this is needed and would save money on unnecessary medical interventions.
- Supportive and palliative care during and after treatment can be cost effective in reducing clinical time i.e. access to palliative support can be cost effective and improve outcomes. See recent NEJM paper on Lung Cancer treatment vs palliation in the US
- Would encourage and support models of self management/supported self management (as in the survivorship research programme) which have potential for delivery of future services which are both cost effective and quality of life enhancing

## 5. How best can quality and outcomes in cancer care be measured?

What are the important quality and outcome measures? These must include reduced mortality, improved disease free survival, reduced recurrence rates, reduced metastatic incidence, Improved quality of life (less invasive, unpleasant treatments), fewer complications, fewer side effects during and post treatment

We approve of the proposed Patient Reported Outcomes Measures and feel that it is very important that patients are involved in designing and evaluating these measures.

### ***Registries & Data Collection***

We think that the National Cancer Intelligence Network is doing fantastic work. Our UK cancer registry is probably the best in the world and is central to determining quality and outcomes. It is very important to maintain and continue to improve this unique resource.

We need to standardise data collection and to understand which interventions make a difference to improving outcomes. Claimed improvements in outcome can be based on unreliable data and statistical analysis.

The proposed power transfer to GPs could pose serious problems for future reliable data collection. GPs are generalists and there is a huge risk that the record keeping on high risk individuals, which has been kept by consultants to date, will be lost were this work to be undertaken by small teams of GPs with less detailed knowledge of each specialism. It would be unreasonable to expect them to be able to compile reliable information. Survival data could become impossible to collate effectively.

We need to be able to access reliable information regarding reduced mortality but also reduced recurrence and metastatic disease and improved disease-free survival, and quality of life. We believe that data should be collected on recurrences as well as deaths from cancer.

More detailed data are needed on:

- waiting times for each part of the patient journey
- length of time from first presentation at the GP to referral and treatment
- the time between surgery and radiotherapy diagnosis and staging
- treatment, including type of surgery
- and side effects
- repeat surgery
- time to recurrence
- 1, 5 & 10 year survival
- availability of other services eg fertility, lymphoedema, reconstruction
- patient compliance with ongoing treatment and the effect of non-compliance, patient reported (and defined) outcomes and complications
- the long term effects of treatment

There is currently a lack of follow-up data. We consider it incredible that this information is not routinely collected. Patients could be involved in the supplying of data via IT based in out patients departments. Data collection could also be nurse led (good example ICR template for long-term data collection).

Electronic records would facilitate better data collection and retrieval/collaboration but also enable more effective planning of future services.

All units should have facility for self-reporting by patients to enter information about side effects, QOL, problems/worries similar to the Yellow Card Scheme. These should be included in the Patient Reported Outcome Measures

We consider that a system of centralised collection of patient reported problems, eg side effects of treatment, needs to be established. Data collection should be more centralised and available – eg BCOM Prof Gill Lawrence

## 6. What further action is required to improve patients' experience of treatment and care?

### ***Clinical Nurse Specialist***

We have emphasised the importance of clinical nurse specialises to the patient pathway in the answer to almost every question. This section is no exception.

The role of these nurses is extremely highly valued by cancer patients and they are crucial in enhancing the patient experience. The psychological aspects of care are just as important as the physiological and that is where the Clinical Nurse Specialists have a particular role to play.

Clinical Nurse Specialists improve patients' experience of treatment and care by:

- helping to cope with difficult information/emotional feelings
- Explaining clinical information in a clear and comprehensible way
- providing psychosocial care of patient
- signposting patients to more help
- recognising the needs of carers.
- running rapid access & triage clinics
- providing continuity of care and continuity in follow-up clinics

### ***Screening***

We need a proper, open debate about the benefits/harms of cancer screening and its affordability – including a review of the extent to which pathologists agree on screening cytology and histopathology diagnoses. Data exist in borderline cases showing that there can be considerable differences of opinion between pathologists.

We understand that the new leaflet on breast screening will be more informative and give a more open resume of the “pros & cons” of screening. We understand that women will have access to further information, if required, to enable them to make their own decisions about screening and treatment. However, until better biomarkers are developed the treatment of DCIS will continue to be based on best known evidence and this needs to be explained to patients with this diagnosis.

There appears to be a difference of opinion between the NCSS and the NBCSS about screening – we would suggest that there should be an open and honest acknowledgement of the lack of knowledge – “this is the best available information at present”

### ***More and Effective Patient Input***

We very much like “No decision about me without me”

We strongly value the existing cancer networks and the opportunities they offer for patient and public involvement in enhancing service delivery, patient outcomes and clinical research.

- More support for patients to enable more effective input into these Cancer Network Partnership and Site Specific Groups.

- More patient involvement in decision making at all levels of personal and organisational psychosocial care and at all levels of cancer service delivery.

Medical and other training would benefit from patient input. For example, cancer patients already contribute to curriculum design and teaching in a number of teaching institutions

- This should be extended
- Patients rather than actors should be used where possible.

We approve of the proposed Patient Reported Outcomes Measures and feel that it is essential that patients are involved in designing and evaluating these measures.

- Need for readily available cards for patients to make suggestions for improving the experience of future patients.
- Patients need to be confident that these will be viewed as constructive/valuable and that a response will be received. An excellent example is found at Bristol Royal Infirmary Radiotherapy dept.
- Need for centralised collection of patient reported problems (eg side effects of treatment) similar to the Yellow Card System for the side effects of drugs
- Opportunities for patient and public involvement need to be widely publicised using all available means eg social networking.
- PROMs should be used in Peer Review.
- Clinical Excellence Awards to be based on PROMs

### ***Improve the language of all who come into contact with patients***

Both patients and those treating them must be able to understand each other and to communicate. Patients need to understand what the medical staff are saying and the medical staff need to be able to understand the patient. This requires that medical staff use simple and sympathetic language and that they speak clear and comprehensive English.

### ***Better Patient information***

It is important that people affected by cancer have a positive approach as this impacts on how they cope with treatment and their hopes for the future. The psychological aspects of care are just as important as the physiological.

- Clear and honest patient information, with no hidden agenda or bias, will enable a more informed patient choice. This is facilitated by increased patient input to the design of all patient information literature.
- Patient held records – as per the ante-natal shared-care card – would facilitate collaboration between hospitals, between hospital and GP and keep the patient and family informed and feeling that they have an active role in their treatment. This could be in the form of memory sticks for those with access to computers – as per Central South Coast Network for chemo patients.

### ***NICE recommendations and Improving Outcomes Guidelines***

Measurable Data are needed to show that, when Cancer Improving Outcomes Guidelines are implemented, they deliver measurably improved outcomes which will improve the patient experience of both treatment and care.

- If improvements are not delivered, the provider should be required to produce an action plan to achieve them.

- More publicity should be given to the drugs that NICE does approve and these should then be funded (including treatment costs).

### ***Regulation of Private Health Care Providers***

Proper Q.A. and regulation/inspection of Independent (Private) Treatment Centres including reporting “How many medical negligence claims?” and “How many patients have to be referred to NHS for corrective treatment?” Should be subject to the same quality standards as everyone else

We received considerable anecdotal evidence of poor quality provision by private health care providers. For example; repeat MRIs at an NHS facility due inadequate private MRIs and poor and inconsistent hygiene practices.

### ***Increased NHS staffing***

The need for increased staffing is mentioned in section 3 – particularly in pathology – and we do recognise the considerable improvements in recent years. Treatment Radiographers up 52%, Palliative Medicine 106%, Medical Oncology 77% and Histopathology 31% between 2000 and 2008

## 7. Are you aware of examples of good practice in cancer service delivery which could be replicated?

We are a group of patients with many years' experience of the NHS. We have direct experience ourselves. And, as patient advocates, we have spent many years between us listening to the experiences of others affected by cancer. We feel that we have a particularly valuable input to offer on examples of good practice. Most of the NHS is excellent, full of dedicated and concerned professionals doing their best to improve the lives of cancer patients and their families. The examples we present here come from our own direct experience.

We have summarised the themes from our evidence under specific headings of good practice but have also included at the end some of the individual evidence we received.

### ***Diagnosis***

- One Stop Clinics/Diagnostic Centres. Rapid access (two weeks) to cancer diagnostics is essential – all the experts in one place with the results on the same day. The Breast One Stop clinics at the Royal Marsden, Frenchay, York and UCLH are a very good example of this.
  - First oncology appointment at breast care centre
  - Same day investigations and results/treatment plan.
  - Diagnosis provided by the investigating clinician.
  - Double reported pathology by specialist breast pathologists for ambiguous diagnoses
  - Pathology results (FNA and Core biopsy) available in 24-48 hours, even on days that aren't One Stop.
  - Multi-disciplinary team involvement from the outset
- Surgeons & breast care nurses trained in use of ultrasound as one of the techniques for diagnosis (Frenchay)
- Family history clinics (Avon Breast Screening)
- Well women clinics
  - Staff with more interest and specialist expertise
  - Reduce inequalities through easier access for people reluctant to see GP
- Skin Cancer Unit - Lead Clinician running a community Skin Cancer service (St Georges)
- Frozen section SNB and with accuracy of 97% saves repeat surgery as results given while patient in theatre (Frenchay)

### ***Treatment***

- Clinical Nurse Specialists
  - Vital and central role to improving patient outcomes (Royal Marsden, St George's, UCLH, Frenchay, Kings College Hospital, Velindre, Royal Bournemouth, Leeds)
- Patient Information

- GP letters dictated during consultation and letter given to patient before leaving clinic (Bath radiotherapy department)
- Good Collaboration
  - Effective multidisciplinary team (MTD) working (Royal Marsden, St George's, UCLH, Frenchay, Kings College Hospital)
  - Secondary breast cancer MDT (Dr Jacintha Abraham, Cardiff)
  - Between hospitals with easy cross referrals to ensure individual patients get most appropriate expertise (Royal Marsden, St George's, UCLH, Royal Bournemouth Hospital Breast Unit)
  - Between medical experts. Regular meetings to share design and recruitment to clinical trials. (NCRI Breast Intergroup)
- Day case surgery for breast conservation patients
  - no drains. Routine use of drains stopped with no difference in infection rate or seroma incidence. Patient support high (Jo Marsden, King's College Hospital)
  - 23 hour pathway for mastectomy patients where appropriate i.e. they stay in hospital a maximum of 23 hours followed by self management of wound drains. (Frenchay, Kings College Hospital)
  - Mammotome procedure uses a large needle and suction to remove most of a lump through just one insertion point (Frenchay)
- Day Case Mastectomy ( King's College Hospital)
  - Routine use of drains stopped with no difference in infection rate or seroma incidence. Patient support high.
- Breast Reconstruction (Frenchay)
  - Dedicated reconstruction clinics
  - Choice in reconstruction/ close working between breast & plastic surgeons, including joint operations. Patient reported outcome study on reconstruction results
  - Nipple tattooing for several years by CNSs
  - Breast reconstruction with fat transplant lipo-vage technique without permanent implants - growing breasts made out of fat in Bristol
- Pro-active lymphoedema prevention
  - This involves seeing and assessing patients pre operatively, giving the patients all the information that they require to make them aware of lymphoedema. Post op patients seen daily with exercises and then at 3 weeks post op attend an outpatient appointment where they are taught scar management, skin care exercises and monitor of arm circumference. Patients seen again at 6 weeks to review and also teach simple lymph drainage. Patients are also given a sleeve for prevention i.e. to wear during radiotherapy, heavy activities such as ironing, cleaning windows, gardening etc. and then are invited on a 6 week rehab scheme to complete education and exercise. Patients are followed up 1-year post op. Although there are many appointments, lymphoedema incidence is now 12% instead of 25% and patients are fully supported. (Wales)

## ***Patient as person***

(All examples from Frenchay)

- Patients are able to request to see specific clinician if desired at reception. Consultants never decline no matter how busy they are.
- Co-location of outpatients and surgery. Surgeons will come out of theatre to provide opinion at outpatients if urgent.
- All patients are offered regular one to one support sessions from the point of diagnosis through to end of treatment. Not many CNSs do this as a regular session (just telephone or if contacted for a one off meeting by the patient) CNS have qualification in counselling skills and refer to psychologists if necessary.
- All patients are seen at time of diagnosis by CNS but return usually in the same week to meet CNS again to discuss surgical options (if applicable), surgery, recovery, social and spiritual needs assessment as well as to talk through the impact of the diagnosis upon themselves and family.
- Office staff rotate onto reception desk to promote patient familiarity when they answer phone calls from patients.
- If patients phone for a prosthesis problem, the clerical staff help them. If prosthesis is broken and patient knows size and product, Frenchay order it to be sent direct to the patient's home - so no need for journey to the clinic
- A young women's support group
- One free reflexology session/indian head massage - provided by volunteers

## ***Extras that make a difference***

- Release of relaxation tapes and Walkman sets from locked cupboard for patients' use.(Leeds)
- Combs and mirrors supplied to urgent admission patients. .(Leeds)
- A seat provided by Friends of the hospital so patients could rest half way up slope from car park (Leeds)
- Pagers given to patients waiting in out-patients, allowing them to use their time usefully if having long waits i.e. leave area to have refreshments or lunch. (Leeds, Frenchay)
- Hospital information booklet mentions the active participation of students and doctors learning new techniques. (Leeds)
- Laminated notices about two-way system communication system in radiotherapy rooms and patient use displayed on changing room cubicle.

## ***Follow-up***

- Open access follow-up clinics. At the end of treatment patients are not put on routine follow-ups, but given information to allow them rapid access to appointments when required. They continue to have any routine tests i.e. mammograms, MRI etc, but are not routinely seen in clinic unless they request an appointment thus saving money. In most cases patients have felt positive about the system.
  - Mount Vernon & Hillingdon "Open Access" follow-up service within a week when needed
  - UCLH Open access within a week to oncologist when needed
  - Specialist nurses for follow-up/triage and rapid access ( Bristol , St George's)

- Nurse led follow-up at annual mammogram successful (radiographer led in Cardiff)
  - Patient “conferences” to develop better awareness of how and when to act , instil confidence in getting back into system , and the support available. Different model of patient- triggered follow up carefully tested in gynaecological cancers positive responses; much clinical time saved. (Sussex)
  - Distress thermometer in 6 month and 12 month follow up clinics, Nurse led outreach/follow up clinics - a pilot in the community, Nurse led hormone therapy clinics, Annual follow up mammogram for 10 years (Frenchay)
- Post treatment services. Urology Unit - Enhanced Recovery Programme (ERP) has been rolled out service-wide. This has reduced patient stay and increased recovery time. (St Georges)

### ***Patient Information promoting better understanding of pathology***

- Patient Access to pathologist to discuss results (Oxford) only works if few take up! But those who do find very valuable, helping understand her diagnoses & treatment plans
- Patient co-design of path leaflet so patients better understand the service and its importance to their diagnosis and care (Sussex)

### ***Supportive and Palliative care***

- Early referral to supportive and palliative care. Routine referral of patients newly diagnosed with secondary breast cancer to provide support services, for example, reclining chairs, extra hand-rails on stairs, entryphone, pain control, social worker (UCLH referral to Islington ELiPSe team)
- Use of gadgets as used in a study at Surrey University enables patients at home to continuously update hospital staff and to receive advice/reassurance, which enables them to stay at home longer – this is also being used in palliative care. It is a major benefit to patients who wish to remain in their own homes as much as possible and enables them to retain some control over their care.

### ***Psychosocial***

- New psychology measures now running. Services will be peer reviewed against them. These are a way of continuing to improve the patient experience. Psychological Support Measures are issued as part of the Manual for Cancer Services 2008. The measures can be found in the Cancer Section on the Department of Health web-site [www.dh.gov.uk](http://www.dh.gov.uk) or the CQuINS web-site [www.cquins.nhs.uk](http://www.cquins.nhs.uk))
- Partnership Group of Sussex cancer network runs annual awards for exceptional care: open to public and staff nominations, judged by patients and carers. Winners have included staff working in palliative care of children, in innovative access to information , in providing bleeps for patients waiting. A way of both rewarding excellence of care and empowerment of patients and of publicising good practice, encouraging its adoption elsewhere.

## *Specific examples*

### **York District Hospital**

- Psychological/counselling support for cancer patients
- A cancer help and information centre
- A breast specialist surgeon
- A breast cancer one-stop-shop
- all now normal practice

### **Leeds**

- Cookridge (cancer) Hospital (no longer functioning – services moved to new Bexley Wing, St James' Hospital, Leeds)
- Release of relaxation tapes and walkman sets from locked cupboard for patients' use.
- Combs and mirrors supplied to urgent admission patients.
- A seat provided by Friends of the hospital so patients could rest half way up slope from car park.
- Discontinuation of males and females sharing 2 toilets with inadequate partition, single wash basin and no private washing facilities.
- Hospital Travel Costs Scheme - a final sentence about the scheme was added to the initial invitation letter to patients – resulted in massive uptake of people collecting benefits (Lymphoedema Department, Wharfedale Hospital, Otley are going to do likewise).
- Pagers given to patients in out-patients, allowing them to use their time usefully if having long waits ie leave area and go and have refreshments or lunch.
- Hospital information booklet mentions the active participation of students and doctors learning new techniques.
- laminated notices about two-way system communication system in radiotherapy rooms and patient use displayed on changing room cubicle.

### **Frenchay Breast Care Centre, Bristol**

Validated by two consultant breast surgeons and centre manager/ breast care nurse. Simon Cawthorn, one of the breast surgeons, is one of the national breast cancer clinical leads:

#### **One Stop Clinics**

- Emphasis on same day investigations and results/treatment plan.
- Diagnosis provided by the investigating clinician.
- Surgeons & breast care nurses trained use ultrasound as one of the techniques for diagnosis

#### **Pathology**

- Double reported pathology by specialist breast pathologists
- Touch Preparation Cytology Reporting for Fine Needle Aspiration (FNA).
- Pathology results (FNA and Core biopsy) available in 24-48 hours, even on days that aren't One Stop.
- Frozen section SNB (Sentinel Node Biopsy) with accuracy of 97% (important as frozen section not widely used because many histopathologists are not prepared to do the work that the Bristol team do - saves repeat surgery as results given while patient in theatre)

#### **Day case surgery for breast conservation patients**

- No drains - and 23 hour pathway for mastectomy patients where appropriate ie they stay in hospital a maximum of 23 hours and then self management of wound drains.  
This now an NCAT project.
- Frenchay are involved in with the aim of formalising 23 hour stay and 48-36 hour stay for reconstruction patients. In comparison, there are a huge number of units who still use wound drains on breast conservation surgery and patients stay as in patients for several days.

### **Breast Reconstruction**

- Dedicated reconstruction clinics
- Choice in reconstruction/ close working between breast & plastic surgeons, including joint operations.
- Patient reported outcome study on reconstruction results
- Nipple tattooing for several years by CNSs

### **Specialist Clinics**

- Lymphoedema clinics
- Results clinics
- first oncology appointment at breast care centre
- follow up clinics/ open access for patients longer term
- distress thermometer in 6 month and 12 month follow up clinics
- nurse led outreach/follow up clinics - a pilot in the community
- nurse led hormone therapy clinics

### **Innovation and Improvement**

- Mammotome procedure - for benign lesions - uses a large needle and suction to remove most of a lump through just one insertion point.
- Lipofiller technique to improve cosmesically after breast conservation surgery
- Breast reconstruction with fat transplant lipo-vage technique without permanent implants - growing breasts made out of fat in Bristol
- <http://www.genesisbiosystems.com/lipivage-systems.html>
- BLES (breast lesion excision system being studied for older patients/ patients with co-morbidities - aim to do under local anaesthetic).
- Service signed up to Breakthrough Breast Cancer Service Pledge

### **“Can Do” culture and teamwork**

- All patients are offered regular one to one support sessions from the point of diagnosis through to end of treatment. Not many CNSs do this as a regular session (just telephone or if contacted for a one off meeting by the patient) CNS have qualification in counselling skills and refer to psychologists if necessary
- All patients are seen at time of diagnosis by CNS but return usually in the same week to meet CNS again to discuss surgical options (if applicable), surgery, recovery, social and spiritual needs assessment as well as to talk through the impact of the diagnosis upon themselves and family
- patients are able to request to see specific clinician if desired at reception. Consultants never decline no matter how busy they are.
- Co location of outpatients and surgery. Surgeons will come out of theatre to provide opinion at outpatients if urgent.

- some pagers to enable patients to go and have a coffee while waiting to be seen or for results.
- clinic and office volunteers
- Office staff rotate onto reception desk to promote patient familiarity when they phone in
- If patients phone for a prosthesis problem, the clerical staff help them. If prosthesis is broken and patient knows size and product, Frenchay order it to be sent direct to the patient's home - so no need for journey to the clinic

#### **Follow up**

- annual follow up mammogram at Frenchay for 10 years

#### **Support Services**

- physiotherapy support
- One free reflexology session/indian head massage - provided by volunteers
- referrals to Bristol Homeopathic Hospital for patients who wish to use its services.
- A young women's support group <http://www.youngwomen4youngwomen.com/>
- A dedicated fundraising charity [www.bustbristol.co.uk](http://www.bustbristol.co.uk)

#### **Research and Education**

- leading centre for trials (IBIS I & II)
- Also excellent research team, who promote accrual to trials and also provide CNS type support as well.
- Six monthly Bristol unit educational evening to share local practice.

#### **Family History Clinics**

- Run by Avon Breast Screening.

#### **University College Hospital London**

- One-stop-shop. Diagnosis on same day
- Multidisciplinary team working
- Rapid referral to support and palliative care services
- Open access follow-up within one week
- Centre for clinical trials

#### **Sussex cancer network**

Partnership Group of Sussex cancer network runs annual awards for exceptional care: open to public & staff nominations, judged by patients & carers. Winners have included staff working in palliative care of children, in innovative access to info, in providing bleeps for patients waiting...A way of both rewarding excellence of care & empowerment of patients and of publicising good practice, encouraging its adoption elsewhere

## **8. What developments in prevention, screening, diagnosis, treatment or after care can be expected which will impact upon the way in which cancer services need to be commissioned or delivered?**

In our discussions with patients, cancer researchers, clinicians and pharma, we have heard about a great number of very exciting new developments in the cancer world. However, as a group, we are concerned about the future development of many of these initiatives in the proposed new GP led commissioning model. We feel that a great many of the new cancer developments will require specialist commissioning knowledge and experience which is unlikely to be available at the GP consortia level. We would like to see cancer services commissioned by specialist cancer commissioners, to retain and to build on patient involvement in future commissioning of cancer services, and to help maintain focus on patient concerns & priorities

### ***Radiotherapy***

We are pleased that there has been a considerable increase in radiotherapy cancer treatments. Radiotherapy treatment times have already been reduced after very successful trials in the UK have shown this to be safe. To ensure these clinically essential services are enabled to develop, central funding as well as expert commissioning is needed for these highly capital intensive projects

- Global clinical trials into Intra-operative radiotherapy, IMRT and IGRT are underway at the moment and could make a huge impact in improving the patient experience by further reducing treatment times and radiation exposure. But, funding needs to be provided to ensure the equipment and staff are available for all suitable patients.
- Cyberknife radiotherapy will provide effective treatment with greatly reduced damage to adjacent tissue – especially valuable in neurological and prostate cancer as well as treating spinal metastases
- Existing radiotherapy research and treatments also need investment (as recommended by the National Radiotherapy Advisory Group) to redress the historical underinvestment and to provide for future needs. Investment in trained staff as well as equipment is required.

### ***Better data collection and storage***

The future must be with electronic records. In this digital age it is quite amazing to go to a hospital appointment accompanied by a huge pile of paper notes – often many folders held together by elastic bands – that is if they have been found!!

Electronic records must surely involve some form of national coordination and not be up to each individual GP consortium and foundation hospital? It is essential that they have improved security as well as access –

Electronic Records will enable:

- increased quality of data collected to improve validity of results and improve longer term benefit to patients
- better data collecting
- earlier assessment and treatment of problems eg neutropenia in patients receiving chemo.
- much better co-ordination of care between different hospitals and between hospital and community care.

### ***Biobanks***

For cancer research to progress researchers need access to high quality biobanks - bespoke tissue provided by specialist tissue banks. These will require some form of central specialised commissioning

- Biobanks should be a “centre of excellence” and not funded at all centres but should give regulated access to tissue by accredited researchers who should be required to share results of any research .
- All patients should be given the option of donating tissue removed at biopsy or during surgery for use in research – current and future.
- Information about tissue donation should be part of the routine consent process prior to surgery. (The information booklet used by the UKBioBank is excellent)

### ***Digital Technology***

Especially valuable in video-conferencing which enables national/ global discussion and dissemination of data, opinion, joint research but is also valuable in MDT meetings. Will improve quality of screening and treatment images and enable easier access during MDTs. However, although the CRS said all screening centres should have at least 1 full field digital machine by 2010, we understand that a maximum of 50% have this and only 6 are fully converted.

### ***Use of gadgets***

As used in a study at Surrey University enables patients at home to continuously update hospital staff and to receive advice/reassurance which enables them to stay at home longer – this is also being used in palliative care. It is a major benefit to patients who wish to remain in their own homes as much as possible and enables them to retain some control over their care.

### ***Biomarkers***

Increasing development and use will reduce cost and improve quality – use will reduce ineffective treatments and patients having side effects with no actual benefit whilst improving outcomes for those for whom treatment is appropriate.

### ***Diagnostic Centres***

These should be based in hospitals but not in clinics for patients already diagnosed and in treatment. They could be based on a triage system run by the CNS with ready access to consultant as needed. They would need better education of both GPs and patients to ensure acceptability and appropriate referrals. Referral to and from the triage clinic should be swift, and further appointments should be made immediately but with some flexibility to enable real patient choice after gaining full information and advice.

## **9. Looking at the plans set out in the White Paper and associated consultation documents (to be published shortly), what are the issues and opportunities for delivering cancer services and improved outcomes?**

We have not had time to read all of this - nor the numerous consultation documents which followed. We are still wading through huge amounts of paper and found the language unhelpful – it is an excellent example of “ticking the box” for public consultation whilst making it almost impossible for most members of the public to be able to access and respond within the required time-frame.

This meets government requirements but NOT the public’s need for proper consultation.

There was general concern about GP consortia led commissioning for such specialist services as cancer. GPs by their very nature are generalists and cannot be expected to have the in-depth knowledge and experience to commission cancer services. Individual GPs will not see enough cancer patients – On average a GP will see one breast cancer patient a year and some of the rare cancers once in a career if at all. We believe GPs are not the best people to commission cancer services. We are also concerned that GPs will be overly influenced by financial considerations rather than the best interests of patients because they are all now businesses.

### ***Individual Comments***

#### **Response 1**

*This is a difficult task, however this is my response, which is from a London based NHS Supporter alarmed at this White Paper, especially the proposal for a GP led consortia. How will this affect the so-called redesigned services - will this mean centres of excellence in urban areas - smaller hubs in rural areas? So: how could you choose? even if you wanted to. I want to go to the hospital, GP practice or whatever health provider that best suits my needs. And however you look at it we have to start at the beginning and that means primary care usually, unless it is an emergency, accident etc.*

*At the beginning cancer could be termed chronic, so we have time to assess the opinion of our GP and where we should go for a prognosis of the suspected condition. In London any of the major teaching hospitals, usually the most local is the correct provider. It is unlikely we would know the name of the Surgeon or Consultant who is considered one of the best in his/or her field for our needs. I expect there are circumstances where people may need to decide between being treated at small non-specialist hospital closer to home or a hospital with specialist facilities further way.*

*Who would provide this information then and where should we access it?*

*I dislike this idea of a "league of the best" all gleaned from the internet for the cleanest, availability of parking, highly ranked doctors, nurses, etc. And I dislike the idea of the patient knows best even*

more. I rely and trust the care all the NHS clinicians have provided my family and myself over the years. Of course, not everything is perfect and sadly mistakes are made but the changes envisaged will be to the detriment of the poorest in our communities. Surely we are not going to roll over and accept this so called Liberation of the NHS.

#### *Patient choice?*

*How could you choose - if you wanted. I would want to go to the hospital, GP practice or whatever health provider that best suits my needs. When I had my prognosis I relied, rightly, on the expertise of my Doctor and finally my Surgeon. My husband, had a ruptured aorta - no choice there, the wonderful ambulance team knew where to take him - and quickly - to Kings. This current view that patient knows best is barmy. Of course, if it is a chronic disease we work in partnership with our clinicians - if it is acute we have to rely on those clinicians who are looking after us.*

## **Response 2**

*1.0 These are my comments from a perusal of the white paper and executive summary. I haven't downloaded the doc or printed it out so my comments are from my notes and therefore I can have got the wrong end of the stick. With this caveat here goes.*

*1.1 White paper produced by DOH on 12/07/10 of 61 pages. I found the executive summary helpful. I like the principles of FREE at point of service, COMPREHENSIVE and CLINICALLY LED. The NHS spend will not be subject to the swinging cuts across other public sectors. Ambivalent by this political decision as it means every other sector gets hit harder but on the positive side this is an opportunity for the NHS to use its resources wisely and thoughtfully.*

*1.2 I'm very happy with the central premise of putting the PATIENT FIRST. GREATER CHOICE AND CONTROL fine, 'no decision about me without me' as a control freak this ticks all my boxes. The second premise INFO. REVOLUTION, is great in principle however I have never seen one public sector body manage the technological implications without spending 10 times original cost, making consultants vastly wealthy and delivering a product that fails at worst or delivers a system that is not fit for purpose! These endeavours can swallow up enormous resource in person power, frustrate the staff and end up delivering so little benefit to front line patient care at huge financial cost. Most info revolutions tend to feed the voracious appetite of government targets that are subject to a constant change as whim and fancy take over making long term planning nigh on impossible.*

*1.3 Patients to have access and choice of any PROVIDER, choice of CONSULTANT LED team and G.P. practice. Patients to RATE hospital and clinical dept and hospital to be open about their MISTAKES. Sentiments great in principle impossible in practice. How is the patient going to be able to decide the evidence and best practice plus availability of one provider against another? If everyone somehow makes a choice and all choose one provider what happens when place not available? Will the less popular hospitals go bankrupt? This could mean some patients may have no local provision and forced to travel huge distances.*

*1.4 Introduce a CONSUMER CHAMPION based in Care Quality Commission. What powers and role will this deliver? Is this a token form of patronage for a political party to wield in a 'friend' who will receive a nice income for looking good? A sort of Kate Moss figure for the public.*

*1.5 The White Paper to remove targets with no clinical justification. Which are these and who decides, based on what criteria? The notion that it is easy to do away with them leaving a tight easily managed universal clinical based set of targets that satisfy the need of the organisations requires some one with superpowers. A target by its very nature measures a point of time and*

activity; it therefore excludes other information. Who can predict which data plus information is crucial to collect when often the question we want to solve hasn't yet been set? The ethical debates will render any possibility of extracting meaningful data difficult in the extreme.

1.6 The role of NICE will include the role of informing commissioning of all care and payment systems. How? Which means what exactly?

1.7 Pay drug companies according to the VALUE of the new medicines. To promote innovation and ensure better access to effective drugs which improves value for money. Who determines value, based on which criteria? Drug companies are global money making profit based companies. Their power bases are enormous. Britain is one small island and for a global company they can do business anywhere. Everyone wants drugs that will heal and add value to a person's life. The reality is that market forces often drive medical efficacy.

1.8 The creation of a new CANCER DRUG FUND from April 2011 created to support patients to get drugs that doctors recommend. Great; however who pays and who determines which drug falls into that category. New drugs are often the ones which are most contentious and the drug companies need to sell them. We often don't know their true value for many years. Is mortality reduction the guiding judgement or quality of life or patient choice? Patient choice is the new mantra. What position does this put the clinician in? My involvement in budget management in a local PCT was that this area was incredibly difficult to manage, balancing clinical need with finite resources.

£100m is not going to go far. At all. I think this is political, not clinical. There is no additional funding to support the administration of those drugs

2.0 My favourite bit of the white paper now, that government will devolve power and responsibility for commissioning services to health care professionals closest to patients namely G.P.'s and practice teams in consortia. Devolution of power from central government sounds a great idea if that cuts down on bureaucratic

interference from government and leaves local communities to manage local need. This will obviously mean that health care provision will become a postcode lottery as each community strives to identify their priorities within their budget. This will meet patient need for some, but if your area chooses not to limit IVF treatment and the next region decides not to provide this service as they will put their budget into resource for the older community some of the electorate will be unhappy. How will the political machinery and equal opportunity implications be managed? Where does this leave CLINICAL need and COMPREHENSIVE service and PATIENT CHOICE?

2.1 The local Authority will through democratic legitimacy promote the joining up of local NHS service with social care and health improvement. From my example at 2.0 it will be interesting to see the outcomes. Local Authorities from all the time I have been associated with them and health communities (30 years in my working life) have always tried to work together to manage need. The difficulties have always been artificial barriers that mean organisations work in silos. Wages, job specifications, different accountable management and separate targets for each service create the mismatch. This is not an essential characteristic of a human but rather an industry predicated on difference and power. Services to be responsive to the public it serves need to start with the individual and the community and build structures that work seamlessly. The name of the provider really doesn't matter a jot as long as the need is addressed that delivers the service in the most effective way to provide value to the person in need.

2.2 The major hindrance to seamless provision of quality is the endless changing of structures and constant turmoil that ensures nothing is medium or long term. Short term fire fighting, patching systems that constantly rearrange then evolve into a greater morass of inconsistencies

and short term targets. This White Paper alongside the other white papers is the latest example of the progress of spin and rhetoric; a characteristic of short term planning- a feature of successive government regimes.

2.3 This model wants to devolve decision making and corresponding resources from PCT's and SHA's to G.P.'s and consortia. Just to be clear this means NHS funding and decision over commissioning being made by groups that are private contractors who exist to make profit! Call me cynical but this is PRIVATISATION. How much will this cost the tax payer when the next government discovers this model of service delivery is deeply flawed? The power of the consultants and the BMA created the significant flaw in the creation of the NHS in 1948

2.4 It is a short time ago that GP's entered into the last contract with the NHS and became well paid private contractors who could hibernate out of hours service. The experience of a small number of the more vulnerable patients who had the misfortune to need medical care out of hours has been deplorable. Overseas doctors flying over from Europe after their own surgeries to work all night in systems that are unfamiliar to them at one extreme to doctors with no knowledge of the records of their patients making wrong decisions. The good side is that the worry of managing out of hours lies outside the local GP's for management. This improved service, costs substantially more and is administered by the PCT. Is this new service adding quality and value for money for the patient, not sure but I do know that the GP's will be reluctant to take the service back and it would cost the NHS more money to do so.

2.5 The government expects all GP's to form consortia bringing in the skills needed. Who pays for these? Are we just rebadging PCT's?

It will cost money to dismantle PCT's eg. Redundancy payments, reducing recruitment for last years of organisation, throwing away all the stationery, office equipment, selling buildings, breaking rental contracts etc.

2.6 The new consortia need to find established recruits, find premises train advertise etc. The cost is significant before a single patient benefits. Remind me how this is value for money when demand continues to increase?

2.7 A new independent NHS Commissioning board will be created to lead on health outcomes and account for NHS resources. This will promote patient involvement. This will lead on promoting equality and tackle inequality. This is the PCT and SHA's role. Where is the data to come from to do this and why do we need this if central resourcing is no longer the aspiration? The role of local resourcing through the local community surely is the validating body esp. if we are going for local democracy! Oh goody another new bureaucratic structure which will need resourcing and local structures accountable too!

2.8 So we are getting rid of the SHA's; they were due to go the last round of PCT restructuring but clung on to power largely as a result of tenacity and the government didn't know what to do with bits of work that would have no home to go to in the new world!

2.9 The whole of the history of PCT's started out in 2000 creating huge expense and bureaucracy but did build up a network of small communities to deliver local priorities - sounds familiar. It was then changed into bigger units at greater cost as they became rebranded. Hospitals were allowed to become Foundation Trusts as long as they met certain quality standards. Each part of the health community rebranded and sought to increase demand by competing for resources at the expense of their neighbourhood hospital. PCT's and SHA's are public bodies. Foundation Trusts are quasi autonomous entities. Foundation Trusts will become the norm now. In the last 10 years the whole health community has lurched from reorganisation to reorganisation. The greatest output for the user of service is the total inability to understand who does what when. The most stable part of the

*system is the patient with the same range of ill health with the same aspirations of alleviating symptoms, pain and disease so they can lead their own lives.*

*3.0 The aim is to reduce management costs by 45% over the next 4 years. This is whilst dismantling cumbersome structures, developing and creating new structures giving greater autonomy to GP's and keeping drug expenses down whilst increasing patient access to drugs through the all new Cancer Drug fund. This feels a little like Alice in Wonderland; pass me the opium bottle!!*

*3.1 NHS will release £20 billion through efficiency savings in order to reinvest. This money if ever released would need to pay the new improved structures. Tangible benefit to the patient who waits on a trolley in A. & E. as they have a complication with their cancer treatment during out of hours – not a jot!!*

*3.2 NICE operates in the hinterland of QUANGO and with the new plan to abolish Quangos will become a statutory body. It will expand to develop quality standards and social care. Why isn't that Care Quality commission which already exists to regulate and monitor standards?*

*3.3 The promotion and conduct of research will be a core NHS role. This will be through thriving life sciences industry and promoting biomedical research units and academic health science service (3.16 et al). No detail of how this will be achieved, who determines value for money or what type of research will be promoted. Is this laboratory based research, drug funded, psycho social research?*

*3.4 How will patients directly be involved in this activity and how will they find out about research and outcomes? How does the funding for the patient joining in research happen? If money follows patient who manages the cost?*

*3.4 GP's in the new consortia can strip out activities that do not have appreciable benefits for patient's health. How is this done? Who decides how you measure appreciable benefits? Will healthy preventative messages get squeezed out? How do you demonstrate that healthy eating messages delivered in classrooms have the desired effect? Proof of delivery will be over years as the children become parents. The biggest incentive for people to give up smoking is severe illness in themselves or significant other. Is the best value for effort best met when the crisis happens and then you intervene? How do you measure the money spent in that area against approving major surgery for someone morbidly obese with no current ill health?*

*3.5 For some consortia the priorities will be on what delivers the best income for their practice. Which services bring in the most money through inoculation programmes, screening, patient list size and area of practice? Nice leafy suburbs with few pockets of deprivation historically have healthier patients. What incentive will there be for inner city practices with high levels of deprivation or rural isolated communities. Practices with significant aging communities will also have greater need.*

*4.0 Where does this leave the cancer patient and research community? The landscape of the Health and social community will significantly alter. The buzz word will be social enterprise namely hiving off as much as possible, driving local agendas whilst steering a course through the challenges of equality, specialism and financial restraints. Government ownership is from a distance (first crisis and the reality will be interesting).*

*4.1 Everything will be in transition with shadow organisations either expanding or retracting. Professionals will be trying to get to grips with new responsibilities and old challenges whilst precious resource weeps away. Patient care will operate in this transitional landscape with harassed staff and confused patients attempting to get their health care needs addressed. 2012 will see supposedly all new improved Health service, local government, education and police force as*

*we take our seats in London for the Olympic Games! Patients and the individual will be at the heart of these developments.*

*4.2 What can we do? We need to keep shouting for the little guy or gal. The patient with cancer needs the best available evidence to make the right choices for them as individuals. This includes where to be treated, choices to be made, how to access seamless services and how to ensure that the patient determines those choices they want to make or wish to delegate to others. Key workers and quality communication are essential. In hospitals we need not only competent diagnostic methods and clinical team but clean wards, equipment and care. Staff are just as critical who meet social needs through providing all personal care tasks in a manner that preserves dignity and shows respect.*

*4.3 In the research world we need to continue to work with the research community to shape their agenda. The research world needs to move away from everything has to happen in laboratories and the competitive need to be first. Patients, need research to provide quality of life treatments and to recognise the whole need of the patient. They health community need to be brave and ask patients. A well meaning paternalism is disenfranchising. Don't just assume the patient will think a certain way, ask them. No one model fits all.*

*4.4 As patients we need to work with the research community to challenge bureaucracy. Research protocols and ethics and all the other hoops which mean research takes years to progress is ludicrous and wasteful of resources. As patients we do not have the privilege of time we need progress. The system is now riddled with risk adverse procedures. If as a research community we do not want to take any risks then just say and we can let other countries run the programmes. We can then allocate those resources to implementing other countries findings, if they can do it quicker and as good, then they should!! It is disingenuous to set up endless bureaucracy that undermines the basic tenants of research namely to provide better quality outcomes.*

*4.5 We need to challenge the new procedures that will improve our services. How will the new structure add value for the patient? Show us a process map which charts a typical patient experience and identify how their lives will be improved by all these changes.*

*4.6 Finally, this white paper is only the first start in the process. We have seen many White papers goodness knows how many hours have been spent writing them in the first place, then everyone commenting. The process then turning into a Bill and then being bounced around the parliamentary process. The subsequent Act will have been modified, added to, challenged and finally comes into statute in a manner that meets no ones original intensions and proves impossible to implement. The community kicks it around developing a best fit just in time for another change in emphasis. The only constant again is the patient with an illness flailing in a system that should be patient led and the new organisation will deliver this honest!!*

### **Response 3**

- 1. As a patient it is UNACCEPTABLE to have a research model predicated on a bureaucratic mind numbingly slow system that is increasingly inefficient. We have become too wrapped up in minutia that does not add value. The starting premise has to be if you had a blank sheet of paper would you develop the system now in place as a cost effective efficient model to understand and improve health outcomes for patients.*
- 2. The White paper emphasizes the role of research and maintains that the health Budget will be protected BUT must be streamlined to cut down inefficiencies.*
- 3. We owe it to the population to enable the best evidence to be produced at the earliest opportunity for the benefit of everyone.*

4. *Be bold cut the Waste. Challenge the endless duplication and series of hoops that is so risk adverse that nothing happens.*
5. *Risk is a part of life. What is important is to identify those areas that must be done because it saves lives against the rules and regulations designed to eradicate all risk. A quick way to judge this is that for patients life is precious and possibly limited hence the best option has already gone so increase the opportunities to develop IMPROVEMENTS. Inertia isn't research the road is not about activity but OUTCOMES.*
6. *Research in the field of cancer has been blessed with resources not afforded to other conditions therefore we should be at the leading edge and ensuring that we set examples of efficient models to duplicate.*
7. *A lot of the time wasted in the research pathway is by committees and endless ethical considerations that do not produce consistency in outcomes. Get rid of those that do not add value.*
8. *Challenge legislation that doesn't help. A more laissez faire style adopted by our French neighbours may be helpful. If it is an edict that makes no sense smile, mutter and carry on regardless delivering the first class service and refuse to implement it.*
9. *The patient is the pivot for decision making use this resource to add pragmatism and strength.*
10. *How will the research community shine through a whole health regime that is about to turn inwards and fragment. Through all the turmoil it is essential that outcomes enhance COMMUNICATION so that patients get the best service and have the ability to shape the choices for their lives.*

## **Response 4**

*I find myself profoundly disturbed by the proposals in the Health White Paper. It looks to me like the whole scale dismantling of the NHS and back door privatisation. It is proposed that the bulk (80%) of the NHS's money (our money) will be managed by several hundred GP consortia. They will commission services from "any willing provider" The GP consortia will be businesses whose aim is to make money by providing health care.*

*They will commission services from any willing provider – another group of businesses whose aim it is to make a profit out of our health care system. Private sector health care providers are rubbing their hands in glee at the prospect of huge profits from the NHS – providing loss-leading tenders to undercut existing service providers*

*I may be old-fashioned in my views, but I do think it is immoral to make a profit out of health care provision. Health care is a public service paid for by all of us. A profit made is somebody's health care not provided.*

*The only control over the whole process appears to be the rather vague "Patient Reported Outcomes Measures". To what extent will patients have any real say? Patients' choice is much vaunted in the White Paper. How will patients influence the commissioning choices of the GPs? How will a cancer patient with a rare or unusual cancer feedback their "outcomes" to GP consortia? It seems to me that "patient" choice has been assumed to be the same as GPs choice. The last thing the NHS needs at the moment is yet another top-down reorganisation. There will be chaos for years and patients will lose out – and that's before the cost is calculated – an estimated £2bn just for the reorganisation!!!*

## **11. As we develop work to improve cancer outcomes, how can we make sure that we continue to try and tackle inequalities in cancer care?**

### ***Engage with INFORMED Patient & Public Advocacy Groups***

We recognise that it is not possible for anyone to be truly representative but there is a need to ensure some direct patient input and not rely on professionals, academics or charities speaking on behalf of patients because they do not always have an unbiased perception of patient views. Test & develop other form of input to engage with wider section of public

### ***24 hour support***

Ensure that all areas meet a minimum standard of care available over 24hrs. There are wide variations in provision of out of hours care.

Where do cancer patients/carers find advice or assistance after 10pm or on Bank Holidays?

Quote “Macmillan and Breast Cancer Care are good when available but patients feel abandoned and vulnerable overnight” This feeling is particularly acute for the increasing numbers living alone.

An increase is needed in the availability of Marie Curie Nurses to provide carers with overnight respite. Palliative care is often provided by independent sector, mostly charities. This should continue but with some monitoring of quality and continuation of part funding by the government

### ***Improved language***

Continue to improve the language of all who come into contact with patients. Develop (or make more available) pictorial leaflets for those with learning difficulties. Recognise that many patients need to continue a positive approach and that this impacts on how they cope with treatments and with recurrences and metastatic disease. Training of professionals could include a list of “Dos & Don’ts” – compiled with patients.

Ensure training is provided for their carers to help them continue to care when a client has cancer diagnosis and treatment. Patients should be included in developing this further and in assessing what is best practice.

Approach cultural leaders for help in more effectively involving the ethnic minorities in education about cancer – awareness of signs and symptoms, value of early diagnosis/screening, participation in research, importance of compliance with treatment, encouraging early consultation with clinic or GP.

Ask ethnic minority staff and patients to undertake health promotion and body awareness sessions in their communities – giving them the necessary training and resources to do this and to produce more effective patient/public information material.

### ***Work with Age UK...***

...and other third sector organisations, to improve the experience of older patients – research is needed to be better able to assess patients' ability to cope with more toxic treatments. Patients should not be denied access to a treatment or participation in clinical trials because they have reached a certain chronological age. More research needed into the benefits/harms of active treatment of different cancers in the over 70's – which would produce a good database to enable these patients to make choices about their treatment and care.

### ***Patient held records***

Especially in form of memory stick – would facilitate ongoing support for travellers and for any patient away from usual home.

### ***Commissioning bodies***

If GP Consortia are formed, there must be a requirement for proper patient input in commissioning plus other professional representation – maybe appropriate in some areas to include a leader from an ethnic community, rep from Age UK, Mencap etc

### ***Less common cancers***

There should be open and honest discussion of the need for specialist centres for the less common cancers which cannot be best treated at a DGH – although it may be possible for some patients to be referred back for routine treatments. Most patients will understand they need to travel further to obtain the best possible treatment simply because they have a less common tumour which means fewer professionals are available who have the necessary expertise. This also applies to patients whose treatment requires more specialised equipment which cannot be provided in all centres eg cyber knife radiotherapy

## 12. Key information for informed patient choice

### **Comments on patients' choice:**

*How could you choose - if you wanted? I would want to go to the hospital, GP practice or whatever health provider that best suits my needs. When I had my prognosis I relied, rightly, on the expertise of my Doctor and finally my Surgeon. My husband, as you know, had a ruptured aorta - no choice there, the wonderful ambulance team knew where to take him - and quickly - to Kings. This current view that patient knows best is barmy. Of course, if it is a chronic disease we work in partnership with our clinicians - if it is acute we have to rely on those clinicians who are looking after us.*

*Many want different choices at different stages of cancer journey; even for any one patient as every, real choice that is genuinely equitable needs support in information, decision making aids etc.. And the choices need to be about the issues patients wish choice about; not those that others have decided for us or imposed.*

*My 28 year old niece was recently diagnosed with Hodgkin lymphoma. I wanted to find out if the hospital she was being treated at was the best. She lives in London so I assumed there would be quite a lot of choice unlike most other areas of the UK. (How will patient choice operate when there only a few specialist centres available?) I couldn't find out anything useful about lymphoma treatment in London - never mind Hodgkin. By contrast, I need to have my gall bladder out and the NHS choices web site was excellent. Told me all I needed to know and helped me make an informed choice - or rather that my preferred local hospital was OK.*

	<b>Theme</b>	<b>Information required</b>
	<b><i>All this information should be available for private hospitals /clinics as well as the NHS</i></b>	
1	Specialisation	Does the hospital specialise in my condition?
2	Surgical experience	What is the experience of the surgical team(s)? <ul style="list-style-type: none"> <li>• How many patients have they treated in the past 5 years?</li> <li>• How many has each relevant surgeon done?</li> </ul>
3	Surgical outcomes	What are their outcomes in terms of: <ul style="list-style-type: none"> <li>• Repeat surgery/readmissions?</li> <li>• Treatment-related mortality?</li> <li>• Remission rates?</li> <li>• Long term cures?</li> </ul> Benchmarked against other hospitals at 1,5,10 and 15 years
4	Specialist services	What specialist services are available on-site? <ul style="list-style-type: none"> <li>• imaging facilities</li> <li>• pathology</li> <li>• stoma</li> <li>• lymphoedema</li> <li>• fertility</li> <li>• plastic surgery</li> <li>• speech therapy</li> <li>• dietician</li> </ul>
5	The team	Who is on the MDT – specialist nurses, pathologists, haematologists, radiologists, surgeons etc.? <p>How many clinical nurse specialists are available for my kind of cancer?</p> <p>What is the ratio of nurses to patients compared to other hospitals?</p> <p>How are the people treating me reached out of hours?</p> <p>Will I see the same clinician at each visit?</p>
6	Waiting times	What are the waiting times, and how do they compare with other hospitals, for: <ul style="list-style-type: none"> <li>• Diagnostic tests?</li> <li>• Surgery?</li> <li>• Radiotherapy?</li> <li>• Chemotherapy?</li> </ul>
7	Clinical trials	What percentage of patients with my condition are involved in clinical trials? <p>Are there any for novel or experimental treatments?</p>
8	Patient satisfaction	How does overall patient satisfaction among cancer patients (if possible, patients with my cancer) compare with those in other hospitals?
9	Hospital-acquired infections	What's their record on MSRA/CD/ other hospital-acquired infections? How does it compare with others?
10	Parking	Is there enough parking at peak times? <p>How much does it cost?</p> <p>Do chemotherapy patients have to pay?</p>

## 13. Contributors

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## 14. Appendix 1 - ICPV Clinical Trials Leaflet

EVERY PATIENT IS A **V**ERY **I**MPORTANT **P**ERSON!

This is a message to all patients undergoing tests and treatments for cancer from a group of patients who have completed our treatment. We are active participants in research which will lead to improvements in the diagnosis and treatment of cancer. You could join with us to help make a difference.

For some people, cancer diagnosis and treatment can be a very stressful time but, we have heard from many patients that they would have liked to have been given more information about current research and to have been given the choice to participate – even if this would only have been of benefit to others.

You could be very influential in improving services and treatments for future patients. You could take part in clinical trials. Or, after your treatment, you could add your unique patient perspective to the design and conduct of clinical trials. Clearly, you could withdraw at any stage and your standard of care would not change.

Breast Cancer is an excellent example of quality clinical research leading to improved treatments and a big increase in survival after treatment. Earlier diagnosis has helped, but the high quality of UK clinical research has been very important. There is now a much greater understanding of the biology of breast cancer and the need to “tailor” treatment for the individual patient.

But, there is so much more to be learned about all cancers. Many more patients need to be offered entry to clinical trials. And, clinical research needs input from the unique patients’ perspective.

HOW CAN YOU BECOME INVOLVED?

- 1) Ask your Nurse or Doctor about clinical trials or studies which may be appropriate for you.
- 2) Ask if you can donate blood or tissue to be used in research.
- 3) Ask about opportunities for patients and carers to participate in improving cancer services and research.

## 15. Appendix 2 - ICPV evidence to AMS review

### **AMS review of the regulation and governance of medical research**

Earlier this year, the Academy of Medical Sciences was commissioned by Government to undertake an independent review of the regulation and governance of UK medical research. A first call for evidence inviting views on issues relevant across the regulation and governance framework closed in June 2010. Following the publication of the Department of Health's report on arm's-length bodies (ALB report) in July, the Academy has taken the decision to issue this **second call for evidence** to provide all interested parties with an opportunity to consider the proposals in the ALB report with direct relevance to the regulation of medical research.

This call for evidence focuses on the Government's wish to consider:

- The merits of placing responsibility for different aspects of medical research regulation within a 'single research regulator'.
- The future of the National Research Ethics Service and reorganisation of the research regulatory activities of the Human Tissue Authority and the Human Fertilisation and Embryology Authority.

To ensure that all submissions can be considered within the timeframe in which the Academy has been invited to report:

- Respondents are invited to provide written evidence by 5pm on **Tuesday 31 August**. Submissions by this date will inform the next discussion of the Academy working group undertaking this review.
- Respondents unable to meet this deadline are asked to notify the Academy by 31 August of their intention to submit evidence and to highlight substantive issues that will form the basis of their submission. The final deadline for submissions is 5pm on **Tuesday 14 September**.

### **Response from Independent Cancer Patients' Voice**

This response is from a group whose interest is cancer research but we recognise that your review is about the future of generic medical research.

The proposed reduction in number of organisations involved in regulating medical research is welcome. Also welcome is the recognition of the value of (and the increase in emphasis on) research in Public Health which will improve the nation's health, help in prevention of disease and tackle some of the causes of inequality in health.

As I understand the proposals, the implications of the White Paper for medical research are good in that regulation and governance will be more streamlined with a reduction of the organisations involved this regulation down to a Research Regulator, the Care Quality Commission and the Health and Social Care Information Centre. I feel strongly that the latter will require considerable work to reduce public anxiety over data protection issues - especially regarding "availability to third parties" and "multiplicity of customers"

It makes sense to amalgamate the HTA & HFEA with NRES but it is questionable how high research will be sited on the agenda of the CQC? There has been an increased awareness of the value of medical research to both public health and to the national economy and there needs to be continued enhancement and ring fencing of funding and resources for medical research. I read that the estimated cost of unemployment and sickness absence to the UK economy approximates the current NHS budget - so research resulting in improved health will actually reduce costs. NHS managers should not be able to divert money from research and their performance review should include a review of research participation in their centre. Patients are also becoming more aware of the value of research and this will become a factor in their choice of referral for treatment - a hospital which has established a reputation for quality research will be attractive to potential patients. (examples Royal Marsden, UCH, Christie, Edinburgh, Leeds, Royal Bournemouth)

There has been a reduction in bureaucracy regarding applying for Ethical Approval for trials and a similar reduction should be possible in R&D - a national approval with very limited need for local adjustment would greatly reduce the delays in start-up at some centres and reduce the costs involved. The application of the European Directive should be risk stratified for individual studies eg studies using drugs which have already been in use compared with studies using new drugs.

NICE - drugs which become available through research do have to have some assessment of value before prescribing in NHS but the panel which takes this decision is not always properly balanced, eg the person who is representing 30+ experienced researchers /clinicians and 3 patient advocates on the Breast Clinical Study Group should carry more weight than an individual non-specialist member of the NICE panel when discussing the value of a new breast treatment. Patients who take part in research need to know that any new treatment which results will be fairly assessed for use in the NHS as well as being available privately.

The NHS itself needs protecting from too diverse commissioning - The NHS provides a unique patient base for medical research - patients, data, samples, trials. The potential of this could be threatened by outsourcing and commissioning of services from outside the NHS - eg when pathology is outsourced, the pathologist is not onsite to attend MDTs and to influence the clinicians treating the patients nor to debate research issues with hospital based researchers. This example could be replicated in other areas of research and there is also a concern regarding sharing of data between different bodies - especially if some are commercial. It should be stipulated in contracts that data obtained from patients & for the benefit of patients, must be shared.

Some data collection does not reach the potential provided by the NHS and it varies in devolved nations - The Scottish health records system with each patient having a unique identifier enables much better assessment of longer term effects of treatment and patient compliance with treatment. eg The study from Dundee which showed that a surprising number of patients had discontinued Tamoxifen by 2yrs - researchers could then correlate this with an increased mortality rate. The study was possible because tracking of prescription use/appropriate patients is possible in Scotland. However, the results should be used to better inform all patients

of the risks/benefits of adhering to treatment to ensure they make a properly informed choice about their treatment.

Most patients would want their health data to be available to all accredited researchers but need assurance that the current restrictions applied to electronic patient records will be maintained and, if they wish, they will have control over who has access and information as to the use of the data collected. It is only by better collection of data regarding diagnoses, treatments and outcomes that patients can have true confidence in their own treatment. Therefore, as the Health and Social Care Information Centre in collaboration with NIHR, could improve collection and access for researchers whilst safeguarding confidentiality for patients this is to be welcomed.

Finally, "Healthwatch" could "strengthen the collective voice of patients and service users" - BUT, they too are becoming cynical about the continuing setting up and abolishing of models/organisations in the NHS. Those of us already involved in adding an informed patient voice to cancer research would strongly recommend the strengthening of our voices by ensuring the continuation of the work of the NCRI/ NCRN , Local Cancer Networks - MDTs, SSGs, CPRGs, Peer Review, Cancer Action Team and the All Parliament Cancer Group - all of which actively encourage and facilitate PPI in cancer research. This input could be much more effective if properly resourced and valued by whoever is responsible for funding in future - this has not been the case in many PCTs.

Independent Cancer Patients' Voice September 2010