



## **Patient information conference – workshops**

**12 May 2010**

### **Barriers identified by each group**

1.

Who is responsible for giving the diagnosis? Therefore who is responsible for giving information?

How do we get to the consultants? Its not a clinical priority of staff on the ground – “Patient information provision” is not a core duty, e.g. nobody is identified to keep patient information replenished.

2.

Healthcare professional perceptions

One stop clinics

Time constraints (quick turnaround)

Human rights – right to information

Age – young – emergency Old – long process

Way in which information is communicated

Resources – time, funding

Lack of education

3.

Whose job is it?

Training and education (knowledge)

4.

Emotional impact inhibits ability to take information in

Reality/perception of not enough time to ask

Resources available

Situation/venue

Different use of language

Health literacy

Ethnicity

5.

Finance!

Leadership/responsibility for provision of information?

Lack of time to tailor to individual information needs – staff overwhelmed

Complexity of availability of information

Professional lack of confidence in communication skills

Individuals' emotional distress as a barrier to comprehending information

Difficulties in recording how/when information has been provided

- *Key barrier: Understanding of impact of psychological distress*

6.

Competing targets

Lack of coordination between key people

Lack of awareness from clinicians

Lack of political drivers

Lack of training of healthcare professionals in delivery of information

Time constraints

Lack of resources and support

Geographical access

- *Key barrier: Resources – time, money, staff, facility*

7.

Physical environment

Time/availability

Emotional burden

Language barrier/cultural issues

Lack of knowledge re: staff

Staff making assumptions that information was given

Lack of guidance for staff/role clarity

Professional skills in communication

Consultant ownership of information

8.

Consultants decide what information they think patients need rather than using an information pathway  
Identifying who has responsibility for giving information  
Lack of coordinated team approach  
What is the quality of information being given i.e. who gives verbal information has a big impact on success of information transfer  
Time allowed for consultation  
Skill of person giving information  
Need process for gradually giving information in bite-sized chunks – not overwhelming patients  
Process of evaluating understanding of information by patients  
Structured approach for all of NI re: info  
Individual needs should be identified for *T*  
Need process for recording information given  
Not skilled as assessing the way patient best learns information  
Need for repetition to ensure that patient understands  
Information needs to be updated  
CNS role can break down – need number of people giving information

9.

Regional education – process, skills, resources  
Lack of healthcare professionals' awareness re: information - hard to know what current baseline is  
Timed and tailored care needs time - when is best time to deliver – do we have research for this?  
Lack of observable medical '*spt*'  
Timing – Resources - need of assessing each patient for their individual needs – need more staff to do role – could currently be a paper exercise  
Process agreed - Need research to provide evidence of positive outcomes  
Joined up across the network - Basic language (verbal/non-verbal) skills – expert communications skills

10.

Communication skills / competence  
Time  
Providing too much information at a very difficult time  
Knowing about the core list  
Not having ready access to information  
Discovering what information is appropriate  
Environment  
Doing the activity – but not capturing that it is done  
Not all diseased have an information pathway  
Core information and variance in the importance of certain aspects  
Individual variance – choice  
Readability

11.

Need to be aware of difficulty of absorbing patient information  
At the same time as suffering the shock of diagnosis  
The number of health professionals involved in diagnosis and treatment  
Pre-diagnosis journey time with no information or mis-information

12.

For many cancers, the professional information has not been identified  
Money and resources within the team for e.g. perception of time needed  
Lack of staff awareness of how to access the information  
Fear about giving too much information  
We work across 5 trusts – trying to get a single pathway across these.  
Consultants don't always buy in.  
Staff training on pathways, how to access.  
Patients not receptive to information because of emotional upset.  
Need to target generalists for training for the people who go home and don't see a cancer (nurse?) specialist

13.

Knowledge about 18-25 year olds (e.g. where what treatment access)  
Under-recording of what doing with under 16s  
Conveying what information client received (from one health setting or health professional to another)  
Lack of coordination – voluntary – statutory sectors  
Social care, spiritual etc. not yet embedded in pathway  
Need resources (more money needed when budget reducing) and Trusts commitment  
Geographical challenges – relevant information for location  
It may be inadequate in many areas  
Health professionals' knowledge and awareness needs improving  
Information and support most needed for 'survivors'  
Absence of key worker role to continue support