

TIP-2: The Informed Patient

An EU Framework for Action August 2004

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Related Materials

Electronic copies of the first 'The Informed Patient' report, the literature review, and presentations given by Prof. Don Detmer and Peter Singleton in London, Brussels, Cork, Bad Gastein, Rome, Vienna, Lille, and Florence are available at the Cambridge University Health web-site:

www.jims.cam.ac.uk/research/health/tip/tip_f.html

The previous report is available directly at:

www.jims.cam.ac.uk/research/health/tip/pdf/crstudy.pdf

1 Executive Summary

The *EU Framework for Action* was a recommendation of the first Informed Patient Conference in December 2002, reported in the original The Informed Patient report in May 2003.

In order to take this requirement forward, a further conference was convened at Trinity College Dublin in February 2004 in order to develop a framework of policy actions to improve the provision of health information to patients, their carers, and the public in Europe.

The following sections present this *EU Framework for Action* as developed by Professor Don Detmer and Peter Singleton of Cambridge University Health. These recommendations reflect the deliberations of the Dublin conference participants, though are not necessarily endorsed by the individual participants or their organisations.

It is important for the quality of healthcare and the health of the citizens of Europe that these actions are taken forward in a collaborative and co-ordinated approach. We make suggestions for possible bodies to initiate the actions, bringing together all relevant actors and stakeholders.

It is critical that policy-makers in EU institutions and member states recognise:

- the need to involve the public more fully in their health and healthcare;
- the crucial function that health information plays in effecting this;
- how to deliver such information effectively over time and through as many channels as possible; and that
- a co-ordinated set of actions, such as this Framework, needs to be undertaken rapidly in order to improve the effectiveness of care delivery and to manage total healthcare costs.

EU Framework for Action

The authors see a need to change the basic pattern of healthcare in Europe:

- to more fully involve patients in their health, decision-making about treatment, and in the management of their care;
- to move healthcare from a 'craftsman-oriented' model of care around the doctor as the main source of expertise and decision-maker to a 'process' model focused on the 'patient journey' where all actors, including patients and their carers, play their part, and quality and safety can be built into the system.

This is not trivial and requires significant change in culture, organisation, and infrastructure in order to take place. There can be no doubt that the effective provision of health information infrastructures, based on current information and communication technologies, could greatly help support these changes in working practices, if appropriately targeted at clinician and patients needs.

One of the first steps is to start engaging patients more fully by improving the level, quality, and appropriateness of information they receive, as patients and also as citizens who need to manage their health in order to enjoy a high quality of life.

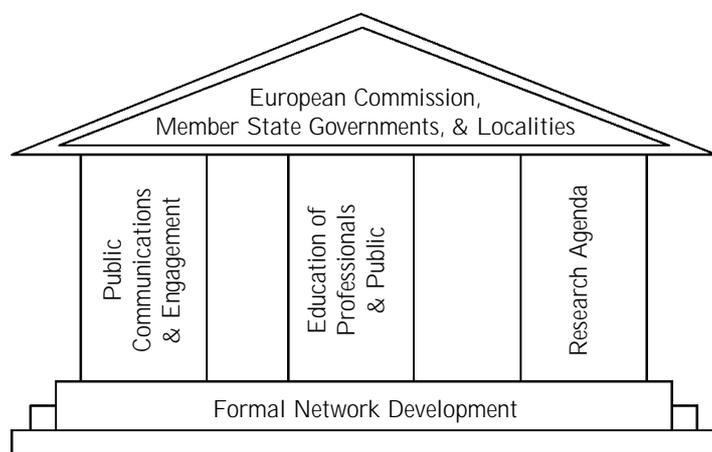


Figure 1 – EU Framework for Action

The EU Framework for Action covers five main areas:

1. Involvement of European Institutions, Member State Governments and Localities
The need for change cuts across institutional and country boundaries and will require both clear leadership and careful co-ordination if change is to be effected and resources not wasted. Effective change occurs within local institutions and teams, supported by national infrastructure and broader policies.
2. Public Communications and Engagement
If the public are to be more fully involved in their care, then they need to have awareness of the issues and a better understanding of health generally. There needs to be a better balance of health information provided so that the public can make appropriate choices (e.g. to avoid MMR scares and the like).
3. Education of Professionals and Public
If patients are to be more fully involved, then professionals will need help in developing skills and techniques to communicate better with patients, both in informing them about their condition and possible treatments and in reaching a shared decision on treatment. Doctors too often see the problem not the patient, and in ‘solving’ the problem fail to support the patient appropriately.
The public too needs to have a better platform of understanding about health so that communications can be more effective and efficient. Social divisions in terms of education and awareness of health issues are reflected in health outcomes experienced by different sectors of society.
4. Research Projects
There are significant areas of uncertainty, as well as aspects that it has not been possible for this study to deal with, which need to be addressed in order to inform future stages.
5. Formal Network Development
There is a need to identify and share good practice in health information provision as too often good practice is established in one locality, but not shared elsewhere. Equally, different options need to be evaluated and compared so that ‘best practice’ can be disseminated and promoted.
A system of networks is required to allow the different actors in the healthcare systems to be able to exchange information, ideally across the various healthcare systems in order to gain from the widest base of knowledge.

Each of these areas is developed in the following pages as:

- Goals
- Strategies
- Immediate Next Steps/Suggested Policy Leads

Under each of the areas, there are relevant current EU initiatives, which are covered in more detail under section 7 – Current activities and initiatives on p33.

2 Goals

	Area/Goal	Explanation/Justification
1.	Involvement of European Institutions, Member State Governments, and Localities	In order to change and improve practice of health information provision, actions must be taken at all levels in the healthcare system, encouraged and supported by activities at a European level.
1A	Acceptance that patient information and involvement needs to be enhanced and coordinated, and adoption of the EU Framework for Action, or a variation	Better information to patients brings a range of benefits as detailed in the TIP-1 report; involving patients in their own care leads to reduced healthcare costs in the longer-term as well as better quality of life for patients; the public needs to be actively engaged in their health if major diseases such as diabetes, coronary heart disease, are to be kept in check and healthcare costs managed effectively. The Framework will need to incorporate all relevant stakeholders, and include sufficient and sustained funding to be viable and meaningful.
1B	Established source(s) for health information capable of engendering public and professional trust	Apart from information provided through healthcare (often partial or poorly presented), the public has a range of sources of health information but few clear indicators as to the quality and reliability of such information.
1C	Higher standards for patient involvement and information provision across Europe	There are instances of best practice across Europe, but there are rarely mechanisms or incentives for the wider dissemination and adoption of good practice within European healthcare systems. Organisations may not be aware of the benefits or realise how simple changes in practice can bring noticeable improvements to the patient experience of care.
2.	Public Communications and Engagement	
2A	Better health and health awareness among the public	This would include health promotion of the importance & value of good health and how to maintain it, e.g., regular exercise, proper diet, and moderating consumption. It will require availability of information on prevention, detection and treatment of disease with active media involvement.
2B	Quality enhancement of media reporting of health issues	There have been health scares that lead to inappropriate responses by policy-makers and the public (e.g. BSE/vCJD, risks of HRT), as well as over-promotion of new techniques (e.g. cancer 'cures') because of simplistic reporting of the issues in the media. A more balanced reporting is needed which presents the issues to educate the public and help them make properly informed decisions, while preserving interest so that articles are still read.
2C	Routes for the public to access information and develop health information skills	Alternative sources of and channels for quality information should be made available to the public to supplement formal information provision, to provide balance, and allow gradual assimilation of material appropriate to the patient's needs.

Area/Goal	Explanation/Justification
3.	
3A	This should not only cover standard personal communication techniques (e.g. listening skills), but also an awareness of patient needs and experience (viz. addressing different social groups, as well as patient concerns rather than medical facts).
3B	Ensure that professions, supported by relevant research, can identify good practice and have incentives to adopt and change to best practice over time.
3C	Any health promotion will rely on existing levels of general knowledge and experience. If the public is not already broadly aware of health issues and how to seek help or further information, then it will be more difficult to communicate a basic message as well as hard for the receivers of the message to then take action. Underlying health education initiatives are required to raise 'health literacy'.
4.	
4A	The TIP reports have sought to bring together published reports of evidence on information provision and its effects, as well as to identify examples of good practice that should be promoted and adopted more widely. This evidence needs to be gathered in a more structured and systematic way across Europe using input from a wide range of centres and bodies.
4B	It is critical that information presented to the public makes clear what level of authority and reliability should be assigned to it. It should be possible to move from a simple statement to the underlying evidence for confirmation, should the reader wish to do so. Evidence must be balanced and impartial in its selection.
4C	Current clinical protocols or care pathways reflect the clinician team perspective, rather than being geared to improving the patient experience, and should include patient information provision as part of the care process. Addressing the wider delivery of care should bring improvements to the quality and co-ordination of care. Components include: patient-oriented evidence-based care protocols for chronic illness management; methods and models that capture relevant patient-reported outcomes; and evaluation of the various methods and models of delivering patient-oriented care and outcomes protocols identified above.
5.	
5A	The networks should promote health and the value of quality health information for public and personal health and healthcare, as well as providing the evidence and methods for effective provision of health information to the public.

3 Strategies

The strategies developed here link to the numbering of the Goals identified in the previous section. Possible actions are developed in the adjoining text, generally under the same numbering scheme, though in some cases some initial research may be required first in order to establish what really needs to be done, in which case these are numbered under Goal 4: Research Agenda. These do not necessarily have to be implemented under the EU Research Frameworks (FP6 & FP7) as they could be done under specific actions for a EC Directorate or funded by some other mechanism.

Area/Strategy	Explanation/Justification
1.	Involvement of European Institutions, Member State Governments, and Localities
1.1	<p>Adopt EU Framework for Action, or a variation, as EU policy in order to promote better practice in health information provision</p> <p>Formal recognition of the need for change is the first step in gaining improvement. The EU Framework for Action as suggested here may be flawed or incomplete, but it is better to start the process of change with an initial plan, and then revise and improve it as experience and evidence develops.</p> <p>Policy initiatives should improve the provision of information to patients and their carers; increase the involvement of patients in their care, and to increase the public involvement in maintaining their health and well-being.</p> <p>Action (1a): Exploit opportunities to promote the EU Framework for Action and TIP principles (e.g. when health issues come to the fore at a national or European level)</p> <p>Action (1b): Bring together stakeholders to co-ordinate actions towards overall policy goals</p>
1.2	<p>Assure sufficient and sustained funding, co-ordination, and leadership for EU Framework for Action, incorporating all relevant stakeholders</p> <p>Because many of the initiatives and actions suggested cross organisation and national boundaries, as well as involving a range of stakeholder groups, there will need to be specific effort to provide this co-ordination and leadership, which will require funding from EU or national sources.</p> <p>Action (1c): Compare current work/initiatives with EU Framework for Action to establish what co-ordination is required and where further action is required</p> <p>Action (1d): Identify where a suitable centre to lead on this topic could best be established to build on existing infrastructure and expertise.</p>
1.3	<p>Interface with relevant portions of private sector to explore and develop public-private partnerships</p> <p>Effective action will require coordination across different stakeholder groups. Sustained change will require all parties to recognise and support that change. Government action alone is unlikely to be sufficient or appropriate unless skills and experience are brought in from other areas.</p> <p>Action (1e): Scope work plan to develop strategies for interfacing with private sector</p>

Area/Strategy	Explanation/Justification
1.4	<p>Evaluate policy options for establishing trusted sources of health information</p> <p>These options would include:</p> <ul style="list-style-type: none"> - an EU-based source (e.g. the European Health Portal) including establishing criteria for such a source - EU-based sanctioned criteria for voluntary application of external sources - An EU-based certification/accreditation process for external sources <p>Action (4a): Establish funding for a research project or working group to explore options for establishing trusted sources of health information and develop proposals</p>
1.5	<p>Develop programme for identifying and disseminating best practice in health information provision</p> <p>As noted earlier, best practice is rarely identified, disseminated, and promoted outside the immediate locality. This can be most efficiently be done at the European level</p> <p>Action (4b): Introduce strand in FP7 for researching best practice in health information provision</p> <p>Action (1f): Develop a proposal for a centre for best practice in health information provision</p> <p>Action (1g): Seek changes in EU regulations to permit more flexible structuring of medicines information for patients as is currently inappropriate for most patients</p>
2.	<p>Public Communications and Engagement</p>
2.1	<p>Develop channel strategy for the various populations and cultures across Europe</p> <p>There is a need to identify the different factors that may affect health promotion campaigns and to what degree these can be co-operative and reinforcing across Europe (rather than being simply run nationally), e.g. how there may be different health-seeking behaviours, preferences for certain channels (e.g. TV versus newspapers), presentation and format issues (to reach certain ethnic segments or disadvantaged groups). Appropriate campaigns can then be developed around a common framework. Experience of the effectiveness of such campaigns can be collated and compared to improve them in the future.</p> <p>Action (4c): Develop research project to review literature and evidence from previous health promotion campaigns in Europe and elsewhere to develop suitable structure and make recommendations.</p>
2.2	<p>Focus health promotion campaigns on specific high-risk conditions addressed to individuals and groups at risk</p> <p>Help the public know about specific high-risk conditions in their regions and how they can reduce their risk. This would not include how to manage the condition, since that would be covered under patient education, though it might enhance awareness of how illnesses may affect people so that others can support those affected more effectively and sympathetically.</p> <p>Action (2a): Identify key areas for European cooperation and what constitutes best practice in running effective campaigns</p> <p>Action (2b): Encourage high-risk individuals to seek medical assessment and preventative treatment</p>

Area/Strategy	Explanation/Justification
2.3 Promote the need for and value of Health Information in itself	<p>It is important to encourage health-information-seeking behaviours by patients and the public generally, and to have this supported within the culture of the healthcare systems in Europe.</p> <p>Explain why health information is important to people, their families, and children, and why patients should normally expect to ask for information, as they need it. It would include techniques for teaching assertiveness and collaboration as well as identifying reliable routes to further information including specific questions patients might ask their doctor or pharmacist regarding generally available medications and equipment.</p> <p>Action (2c): Ensure that professional communications education supports information-seeking behaviour by patients</p> <p>Action (2d): Support information-seeking behaviour as part of general health education in schools</p> <p>Action (2e): Support information-seeking behaviour as part of general health education for adults in employment</p>
2.4 Develop and promote media standards and/or guidelines for infomediaries	<p>There are guidelines such as the ECHN Guidelines for journalists. These may need to be taken further to support other sources (e.g. advertisers, professional bodies, and healthcare suppliers) and to be promoted and adopted by the industry/professions themselves (rather than promoted externally).</p> <p>Action (2f): Assess appropriateness of ECHN guidelines for journalists and seek to gain adoption by main-stream press and/or professional bodies</p> <p>Action (2g): Investigate how EHCN guidelines (or other more appropriate ones) could be applied in other areas</p>
2.5 Produce guidelines for the public in seeking health information	<p>These can include recommended links to quality sources, uses of information channels such as public libraries, the Internet (including general search engines such as Google, and specialist medical sites), as well as how to obtain more information through the healthcare systems. Suggestions such as drawing up a list of what to ask your doctor and that it is the patient's right to have their questions addressed. Links to patient support groups will also be important.</p> <p>Action (2h): Convene panel of representatives from different stakeholder groups to develop this, led by patient groups to ensure that it addresses patient needs</p> <p>Action (2i): Incorporate this functionality into the European Health Portal</p>

Area/Strategy	Explanation/Justification
3.	Education of Professionals and Public
3.1	<p>Ensure that curricula cover all segments of the professions</p> <p>It is important that there are curricula for entry-level ('teaching') as well as for Continuing Professional Education (CPE) ('practice') to influence the new doctors as well as those currently practising. All members of a clinical team need to be aware of the right approach to patient communication, so that it is effectively delivered by the team.</p> <p>Action (3a): Require Continuing Professional Education (CPE) in communications skills</p> <p>Action (3b): Develop appropriate curricula on communicating with patients and the public</p>
3.2	<p>Develop models and methods to support practitioners in their practice settings</p> <p>Teaching principles is important, but changing behaviour also requires provision of appropriate tools and techniques to support the new way of working, e.g. including models of practice where Electronic Health Records link patients with their providers; printed materials that can be adjusted for a variety of local settings.</p> <p>Action (4d): Develop structure for delivery of information throughout 'patient journey', identifying what support tools are available, have been tested/piloted and found useful/effective based on evidence from studies.</p>
3.3	<p>Ensure that initiatives directed at educating and supporting professionals are patient-led/focused and that the approach taken includes informal care-givers as well as patients</p> <p>There is always a danger that curricula and methods are developed by clinicians based on what they perceive as effective communication, which may not accord with what patients really want or need. Involving patients in review boards has usually proved refreshing and gainful, though make take additional time and effort to implement effectively (usually in changing professional attitudes and additional consultation/revisions)</p> <p>Action (3c): Professional bodies and organisation to involve a patient representative or a patient review panel to comment on draft proposals/curricula</p>
3.4	<p>Improve health understanding as part of general 'life skills' education in schools for children, and for adults through workplace initiatives and adult education</p> <p>It should be part of the education process that children are not only trained in academic terms, but given the necessary skills and knowledge to act as a citizen. Where this has not been possible in the past, then steps should be taken to reach out to the wider population through their workplace or other routes. With ongoing changes to medicine and healthcare systems, it is doubly important that adults are properly informed not only for their own decision-making, but so that they too can educate the young.</p> <p>Action (2d): [see above] General health education in schools</p> <p>Action (2e): [see above] General health education for adults in employment</p>

	Area/Strategy	Explanation/Justification
4.	Research Agenda	
4.1	Support a formal research initiative for the gathering of research evidence around health information provision, funded jointly by EU and private sources	Obtaining funding may be difficult under the current FP6 as this topic crosses organisational boundaries. However, FP7 is currently under consultation and may be able to support broader proposals. Additional funds are likely to be needed from either sources, either to 'boot-strap' the process of funding towards developing a consortium of centres to put forward a more complete proposal, or to help long-term running costs. Action (4e): Respond to FP7 Consultation exercise (done 26/07/04 in UK) Action (4f): Review how sub-projects may be developed to fit programmes under 4th call under FP6 or FP7 Action (4g): Identify other possible sources of funding for whom the gathering of research evidence around health information provision is relevant
4.2	Assess state of research in this area, shape a funding strategy to enhance scope and quality of relevant work to assure a sound ongoing infrastructure	Identify existing work, research centres, and possible partners in order to generate a proposal detailing the likely structure of a research centre or network, how the work will develop and be supported by the consortium, and what funding will be required to set up a centre (real or electronic), gather and collate the evidence, provide dissemination activities for best practice methods, and to maintain the necessary infrastructure for the future. Action (4h): Identify possible partners across Europe, and seek funding for initial meetings to start the research initiative
4.3	Create a research and policy initiative that assesses current status of trust and credibility in health information sources and support a dialogue to identify steps that will improve performance	There is evidence from Euromonitor about trust in specific types of resources (e.g. clinician vs media vs politician) but not in the detail of how such trust develops or diminishes. There have been studies on how individuals assess the quality of information over the web, as well as proposals for standards to support trust (e.g. HoN). Action (4i): Develop outline work plan for the 'trust and credibility' study, seek possible partners across Europe, and seek funding from EU and independent sources
4.4	Develop structure for delivery of information throughout 'patient journey', identifying what support tools are available, have been tested/piloted and found useful/effective based on evidence from studies (from action 3b)	The 'Patient Journey' model has consistently found support when presented at meetings and conferences, emphasising that information is not a one-off event, and needs to be tailored to a patient's particular circumstances whenever possible Action (4j): Develop outline project proposal for information around the 'patient journey' and identify possible source(s) of funding (e.g. FP6/FP7)

Area/Strategy	Explanation/Justification
5.	
5.1	<p>Formal Network Development</p> <p>Build a consortium of networks with clear roles for each</p> <p>Three distinct networks are clearly needed:</p> <ul style="list-style-type: none"> · Healthcare Provider Information Network (HPIN) · Healthcare Research Information Network (HRIN) · Health Information Media Network (HIMN) <p>Build on existing networks where possible</p>
5.2	<p>Establish a plan, funding, and implementation of a project to deliver the networks identified above</p>

4 Actions

The actions identified in the previous section are explored here in some more detail, mainly to identify which bodies or organisations might reasonably take a lead to initiating these actions. Such organisations are highlighted (**bold**) in the adjoining text – this does not preclude other bodies from taking part or encouraging action in their own right.

Area/Action		Suggested Lead organisation/Detail
1.	Involvement of European Institutions, Member State Governments, and Localities	
1a	Exploit opportunities to promote the EU Framework for Action and TIP principles (e.g. when health issues come to the fore at a national or European level)	<p>CUH/Johnson & Johnson Centre for Advancing Health Information (CAHI) will both continue to promote this topic. Other organisations who support this initiative, e.g. patient groups, are encouraged to work to promote improvement in the provision of information to patients as active participants in their care.</p> <p>A paper presented by Mrs. Christine Marking, Information to patients and EU policy initiatives: Policy Entry Points, at a CHES round-table meeting on 29th June 2004 is particularly pertinent. It is available at www.euractiv.com/ndbtext/health&food/informed%20patient-eu.doc</p>
1b	Bring together stakeholders to co-ordinate actions towards overall policy goals	<p>There have already been round-table meetings organised by the Centre for Health Ethics and Society (CHES) at the Madariaga Foundation in Brussels, who may run further meetings. Ideally, this needs to be taken up by one of the European institutions. This crosses organisational boundaries within the Commission, but DGs Sanco and InfSo have collaborated closely in the past and would be ideally placed to promote this further. The Environment, Public Health and Food Safety Committee in the European Parliament would also be well placed to explore the possibilities for action and to make recommendations to the Commission.</p>
1c	Compare current work/initiatives with EU Framework for Action to establish what co-ordination is required and where further action is required	<p>Johnson & Johnson CAHI should take this as the next step from the publication of the TIP-2 report, based on some of the information developed here.</p>
1d	Identify where a suitable centre to lead on this topic could best be established to build on existing infrastructure and expertise	<p>This will need to draw on information developed through creation of formal networks (see Area 5 below), based on where expertise and infrastructure already exist.</p> <p>A proposal, including a business model and outline budgets would be needed. Ideally, this should be led by DGs Sanco and InfSo together.</p>
1e	Scope work plan to address strategy for interfacing with private sector	<p>DG Enterprise has already constituted a Working Group following on from the G10 Working Group to review the question of using a public private partnership to improve the quality of existing information available to the public on medicines. This may be limited in its remit and there may be other ways in which the private sector could be involved.</p>

Area/Action	Suggested Lead organisation/Detail
1f	Develop a proposal for a centre for best practice in health information provision
1g	A proposal, including a business model and outline budgets would be needed to gain funding for such a centre or to build on an existing centre and infrastructure. This should be led by the centre identified by action 1d above.
2.	This will need action from both the EMEA (through their Working Group with Patients Organisation) and DG Enterprise who handle recommendations for regulation. Presently, there is action to improve the single Package Insert Leaflet (PIL), but within the constraints of a single 'one size fits all'. Better directions to more detailed sources would be appropriate, if only to allow physicians to obtain more appropriate information for their patients (e.g. allowing for disabilities or other impairments).
2a	Public Communications and Engagement
2a	Identify key areas for European cooperation and what constitutes best practice in running effective health promotion campaigns
2b	Encourage high-risk individuals to seek medical assessment and preventative treatment
2c	Ensure that professional communications education supports information-seeking behaviour by patients
	Identify relevant conditions and the key messages to be addressed; identify appropriate media campaign (probably supported by other initiatives) to raise issues and encourage behaviour change. Possible conditions are: cancer/smoking, diabetes/obesity, CHD, fitness in older people. There is much that is already being done in some of the key areas, either nationally or internationally by WHO (e.g. anti-smoking). However, this is rarely co-ordinated across stakeholder groups, so that campaign actions are reinforcing and well supported at all points. This may be an area that the World Health Organisation could lead on as having implications on a wider basis than just Europe. This will require much public education as to what are high-risk factors in key disease areas, so that individuals can identify themselves appropriately in order to seek support. The national health systems need to be geared up to support a more pro-active role in managing health (rather than treating illness). It may also require changes in practice so that European citizens are more regularly assessed for key factors (e.g. cholesterol) perhaps as part of a regular health assessment programme. This may be a matter for The Council of Ministers to lead on changes in national practice. This could also include promotional activities in the workplace to reach high-risk individuals, particularly men, who may otherwise not seek care. This could be led either by DG Employment or by the Federation of European Employers , though employers generally have not appreciated the benefits of employee health, though there are notable exceptions. It is important that not only should physicians communicate well in presenting information to patients, but that their behaviour and the structure of the consultation supports an active dialogue between patient and physician. It is important that the WMA, CPME, and national medical associations include this within curriculum development (see Action3b below).

	Area/Action	Suggested Lead organisation/Detail
2d	Support information-seeking behaviour as part of general health education in schools	As noted above, action 2(c), the public need to be comfortable in seeking more information from their doctors. This approach needs to be supported through general education, as well as teaching the skills and techniques in finding appropriate health information from other sources, e.g. public libraries, citizen support groups, and the Internet. This is an area that DG Education should seek to foster, either through re-invigoration of the <i>Health Education in Schools</i> initiative, or as part of promoting general life skills to children and students.
2e	Support information-seeking behaviour as part of general health education for adults in employment	Similarly, there is a similar need to support the present adult population in their health-seeking information. An ideal locus for such support is through the workplace and adult education programmes. DG Employment should continue its Health Education in the Workplace initiative, possibly in collaboration with DG Education by linking to adult education initiatives.
2f	Assess appropriateness of EHCN guidelines for journalists and seek to gain adoption by main-stream press and/or professional bodies	This will require considerable work to gain 'buy-in' by individual journalists, their trade bodies, as well as their employing media organisations. Bringing the latter organisations to the table, could best perhaps be done by DG InfSo in terms of consumer affairs regarding poor provision of information to the public, supported by DG Sanco, as a public health issue through inappropriate effects on public health-related behaviour (e.g. shunning MMR vaccinations). The ultimate aim must be to have the EHCN (or adapted) guidelines adopted by journalist trade bodies and supported by the media organisations through their editorial policies. The World Health Organisation (WHO) as the original supporter of EHCN could lead this initiative on a wider arena, which could be more helpful given the global scale of many media organisations.
2g	Investigate how EHCN guidelines (or other more appropriate ones) could be applied in other areas	Journalism, be it print or broadcast, is only one channel for communicating with the public. Other areas need to be considered and supported to ensure that all information provision is appropriate. Advertising is more generally covered by EU legislation, and specifically for prescription-only medicines (POMs). DG InfSo has recently published Quality Criteria for Health Related Websites, which add to a number of guidelines (e.g. HON) for Internet-related sites. A number of guidelines for printed materials have been produced, but could usefully be collated into a general European recommendation. The EMEA, <i>Guideline on the readability of the label and package leaflet of medicinal product for human use</i> , is specifically targeted to PILs and their regulation. This would best be carried forward by DG InfSo and DG Sanco as noted for action 2f, encouraged by patient organisations, ideally the European Patients Forum (EPF), for whom this could be a useful initiative on which to establish its presence.

Area/Action	Suggested Lead organisation/Detail
2h	<p>In European Commission terms, this should be led by DGs Sanco and InfSo, covering public health and consumer affairs. It could be part of the Open Method of Co-ordination on Patient Mobility as citizens will need to know what treatment they are entitled to across the EU, and it makes sense to tie this to the larger area of health information in general. European Patient groups, especially the European Patients Forum, should be active in promoting this to the Commission and the European Parliament.</p>
2i	<p>The European Health Portal, is part of the eHealth initiative run jointly by DGs Sanco and InfSo. Incorporating this facility should be relatively simple, though it is harder to comment further without more detail on the intended functionality of the EHP outside simple exchange of health information between healthcare systems.</p> <p>Again, European Patient groups, especially the European Patients Forum, should be active in promoting this to the Commission and the European Parliament.</p>
3.	
3a	<p>Education of Professionals and Public</p> <p>In the UK, the General Medical Council already requires professionals to undergo CPE training, and this includes communication skills. This approach needs to be adopted more widely by national medical associations across Europe. Steps towards this should be initiated by the CPME and the Standing Committee of Nurses (PCN), linked to WMA initiatives, either by convening a Working Group, or introducing this as a relevant topic for adoption at a conference or council meeting in the near future.</p>
3b	<p>The CPME, the Standing Committee of Nurses (PCN), and national medical associations must work together to develop comparable curricula across Europe. The WMA is already taking steps in this regard and work is already in place in Sweden engaging patients in training physicians.</p>
3c	<p>The European Patients Forum, should be active in suggesting representatives who could take part, and review the draft syllabuses.</p> <p>Finding patients to take part in the delivery of such courses will require close collaboration between medical schools and local patient organisations, ideally supported from national organisations. Patients taking part will also need support and training. A guide or manual could easily be produced at a European level by the CPME and EPF.</p>

Area/Action		Suggested Lead organisation/Detail
4.	Research Agenda	
4a	Establish funding for a research project or working group to explore options for establishing trusted sources of health information and develop proposals	DGs Sanco and InfSo should together establish a working group to build on their work in developing guidelines for web-sites. This should include a literature review to establish what is already known about health information seeking behaviour and what are the barriers and drivers for information seekers.
4b	Introduce strand in FP7 for researching best practice in health information provision	DGs Sanco and InfSo should propose such a strand, supported by input through the national consultation processes by other actors in this field. All organisations should seek to provide comments and recommendations as soon as possible.
4c	Develop research project to review literature and evidence from previous health promotion campaigns in Europe and elsewhere to develop suitable structure and make recommendations	Most health campaigns have been either public health campaigns (e.g. anti-smoking or safe-sex) or 'infomercials' by pharmaceutical companies. Different strategies have been used and have been more or less effective, but these have been reviewed at a national rather than European level. American studies have highlighted the different responses by ethnic groups. This should most naturally be led by DG Sanco, but could be adopted by any European academic institution that has expertise in this area to bring together a consortium of centres across Europe to submit a bid under FP6 or FP7 (or any other funding source).
4d	Develop structure for delivery of information throughout 'patient journey', identifying what support tools are available, have been tested/piloted and found useful/effective based on evidence from studies	This would probably be to be taken forward as a research project, possibly led by DG Sanco, but most likely by a European academic institution that has expertise in this area to bring together a consortium of centres across Europe to submit a bid under FP6 or FP7 (or any other funding source).
4e	Respond to FP7 Consultation exercise	CUH has already submitted comments in the UK. Other actors should seek to provide comments and recommendations as soon as possible.
4f	Review how sub-projects may be developed to fit programmes under 4th call under FP6	DG Research clearly has intimate knowledge of the Sixth Framework, and has already contributed some comments as a CHES meeting in June. It will also require some knowledge of the subject area in order to identify how aspects of the issues raised here might be formulated as projects within the confines of FP6. It is suggested that CUH consider this and arrange a meeting for further discussion at some stage in the near future.

Area/Action	Suggested Lead organisation/Detail
4g	<p>Identify other possible sources of funding for whom the gathering of research evidence around health information provision is relevant</p>
4h	<p>Identify possible partners across Europe, and seek funding for initial meetings to start the research initiative</p>
4i	<p>Develop outline work plan for the 'trust and credibility' study, seek possible partners across Europe, and seek funding from EU and independent sources</p>
4j	<p>Develop outline project proposal for information around the 'patient journey' and identify possible source(s) of funding (e.g. FP6)</p>
5.	<p>Formal Network Development</p>
5a	<p>Identify existing networks and their functions, noting the fit with the requirements for TIP</p>
5b	<p>Identify relevant centres in new member states to be included into networks</p>
5c	<p>Develop a plan for network development, and as a basis for seeking funding</p>
5d	<p>Develop a clear proposal to seek funding and support for a project to deliver the networks over the longer-term</p>
<p>The purpose is to identify possible sources of funding for early stage work towards the development of a centre for health information provision, after which it would be hoped that it would be supported by EU funding or national subscriptions.</p> <p>It is suggested that CUH explore this area with a view to convene a meeting of possible funders and present the wider vision for the Informed Patient, and some of the projects that are needed and could usefully be funded.</p> <p>Some possible partners have already been identified by CUH, and it is hoped that further partners will identify themselves or be suggested to CUH by recipients of this report. It is hoped that a lead partner will emerge who may be able to host the initial meetings.</p> <p>DG InfSo/DG Sanco should jointly lead on establishing a study into policy options for establishing trusted sources of health information (possibly as part of EHP programme).</p> <p>A collaboration of universities and research teams, including the Johnson & Johnson CAHI, should work to put forward a suitable proposal, perhaps for consideration at the meeting suggested under action 4(g) and in light of the output from action 4(f).</p>	<p>These actions form a sequence, but can be led by different organisations depending on the network:</p> <ul style="list-style-type: none"> Healthcare Provider Information Network (HPIN) should be led by DG Sanco Healthcare Research Information Network (HRIN) should be led by the Johnson & Johnson Centre for Advancing Health Communication Health Information Media Network (HIMN) should be led by EHCN/WHO <p>The co-ordination of these actions should best be led by DG Sanco which is already involved in a number of existing networks, which could support or integrate with the networks suggested.</p>

Organisations and Abbreviations mentioned:

Term Used	Full description	Stakeholder Group	Term Used	Full description	Stakeholder Group
DG Sanco	European Commission: Directorate General Health and Consumer Protection	Policy Maker	DG InfSo	European Commission: Directorate General Information Society and Consumer Affairs	Policy Maker
DG Employment	European Commission: Directorate General Employment and Social Affairs	Policy Maker	DG Education	European Commission: Directorate General Education	Policy Maker
CUH	Cambridge University Health	Academic	J & J CAHI	Johnson & Johnson Centre for Advancing Health Information	Academic
CPME	Comité Permanent des Medecins Européens/Standing Committee of Doctors	Professional	EPF	European Patients Forum	Patient
ICN	International Council of Nurses	Professional	WMA	World medical Association	Professional
FEE	Federation of European Employers	Industry	WHO	World Health Organisation	Policy-maker
DG Research	European Commission: Directorate General Research	Policy Maker	EHCN	European Health Communication network	Media
EMA	European Medicines Evaluation Agency	Policy-maker/Regulator			

Action analysis by Stakeholder group

Stakeholder groups which need to be involved are ticked (✓) – the suggested lead is identified by a ticked box (☑)

Stakeholder Group: Actions:	Patients & Public	Professions	Payers/ Public Purse	Policy- makers	Producers/ Industry	Press/Media	Academe & Research
1a) Promote EU Framework for Action (EFA)	✓			✓		✓	☑
1b) Convene stakeholder representatives	✓	✓	✓	☑	✓	✓	✓
1c) Establish EFA fit with current work							☑
1d) Locate Centre for coordination of Health Information				☑			
1e) Work plan for involving private sector				☑	✓		
1f) Proposal for Best Practice centre							☑
1g) EU Regulations to improve PILs				☑			
2a) Best practice in health promotion campaigns	✓			☑			✓
2b) Campaigns to high-risk individuals	✓	✓		☑			
2c) CPE to encourage info-seeking by patients	✓	☑		✓			
2d) Encourage info-seeking by public in schools	✓	✓		☑			
2e) Encourage info-seeking by public in employment	✓	✓		☑	✓		
2f) Assess EHCN Guidelines for industry	✓			☑	✓		
2g) Extend EHCN Guidelines to other channels	✓			☑	✓		✓
2h) Guidelines for patient & public	☑	✓		✓	✓	✓	✓
2i) EHP to support patients in seeking information	✓			☑	✓	✓	
3a) Require CPE in Communication Skills	✓	☑		✓			
3b) Develop curricula in Communication Skills	✓	☑		✓			✓
3c) Involve patients in developing and delivering CPE	☑	✓		✓			

Stakeholder Group: Actions:	Patients & Public	Professions	Payers/ Public Purse	Policy- makers	Producers/ Industry	Press/Media	Academe & Research
4a) Project on trusted sources of health information	✓	✓		☑	✓	✓	✓
4b) Research on best practice in health information	✓	✓		☑	✓	✓	✓
4c) Research on effective health promotion campaigns	✓	✓	✓	☑	✓	✓	✓
4d) Information tools to support care process	✓			☑			✓
4e) Influence FP7 to include health information work	✓	✓		☑	✓		✓
4f) Identify possible projects for FP6				☑			✓
4g) Identify source of funding outside EC	✓		✓	✓	✓	✓	☑
4h) Identify research centres and potential partners	✓	✓		✓	✓		☑
4i) "Trust & Credibility" study				☑			✓
4j) Information needs through 'patient journey'	✓	✓					☑
5a) Identify existing networks and their functions	✓	✓		☑	✓		☑
5b) Identify relevant centres in new member states	✓	✓		☑	✓		☑
5c) Produce plan for network development				☑			☑
5d) Develop proposal for long-term funding for networks				☑	✓		✓

5 Purpose and Scope

Purpose of this document

“The Informed Patient” (TIP) project is a research initiative aimed at supporting evidence-based health policy development on the provision of information to patients in Europe. It aspires to a future when citizens, patients, and their non-professional care-givers are well informed and actively involved in collaborating with health professionals to maintain and improve their own health.

This document presents the recommendations by the Cambridge University Health team for a ‘EU Framework for Action’ to improve the provision of information to patients in Europe, based on discussions with a group of policy experts at a conference in Trinity College Dublin in February 2004, and subsequent comments on various drafts.

The document presents key goals, development strategies, and immediate actions required to initiate this process of improvement in sections 1–4. The discussions from the Dublin conference are summarised in section 6 from which the Framework was developed. Further relevant materials are provided in subsequent sections or appendices.

The development of this Framework through to actions and recommended leads has proved particularly difficult, reflecting that this issue requires co-ordinated effort from the many actors in healthcare. It cuts across organisational boundaries within European institutions, such as the Commission, across the usual sectors of care (primary, secondary, social care, and self-care) and across responsibilities within clinical teams. It requires a holistic view of medicine and care, and challenges existing practice and culture in the way in which healthcare is delivered, which often focuses on the ‘problem’ rather than the ‘person’.

Comments received on a draft version¹ of this Framework suggested that the actions presented might not be sufficiently detailed for actors to adopt within their current powers or agendas. It is planned that the Framework should be developed further in the near future in terms of stakeholder ‘perspectives’ with more detail on what is needed and can be addressed. However, this should not prevent the Framework as presented here from being a meaningful approach which actors, either individually or in collaboration, can adopt and take forward. We urge all players in European healthcare to look positively for what can be achieved or at least initiated from this Framework, which we recognise to be only a first attempt on a broad strategy that needs much further refinement.

The TIP project is a joint effort of Professor Don E. Detmer, MD, MA and Peter Singleton, MBA, both Senior Associates at Cambridge University Health. Cambridge University Health is the health policy and management research centre at the Judge Institute, University of Cambridge, and is referred to variously as ‘CUH’ or ‘Cambridge University Health’. Detmer is also Professor Emeritus and Professor of Medical Education, University of Virginia, Charlottesville, Virginia, USA and Research Director of the newly formed Johnson & Johnson Centre for the Advancement of Health Information based at the College of Europe in Brussels.

Concept and Scope of ‘The Informed Patient’

In the first TIP report², the term ‘Informed Patient’, was taken to refer to people with illnesses (either ‘patients’ receiving care or having conditions deserving treatment), who need appropriate information in order to be properly involved in their healthcare – be it to seek care, decide on the best courses of action with care professionals, or to follow through the agreed course of treatment. It was taken to include non-professionally trained carers as well such individuals as family members and/or friends, since they may serve as proxies for the patient when incapacitated and often are a crucial part of the social unit making decisions for the future.

¹ Presented at a round-table meeting at the Centre for Health, Ethics and Society (CHES) on 29th June 2004

² Available at www.jims.cam.ac.uk/research/health/tip/pdf/crstudy.pdf

It was clear very early in the Dublin deliberations that an EU Framework for Action must widen the scope to include health promotion and education, as well as information for family & carers for both wellness and illness. It is important to recognise the need for a more actively engaged public, not only in terms of deciding about and managing the course of their own treatment, but also in providing guidance and feedback to the healthcare system on the direction and quality of the healthcare it provides.

Interpretation of the term 'EU'

The investigators' intended interpretation of 'EU', in both reports, is the geographical area of Europe covered by the European Economic Community, regardless of the number of its members, e.g., whether before or after 'enlargement' by the 10 accession countries. We note that the 'European Economic Area' (EEA) includes Norway, Iceland, and Liechtenstein, which are not part of the EEC, though may share many cultural and economic (including health) issues and policies.

Since a EU Framework for Action incorporates policy options largely within the remit of the European Commission, some participants joining the Dublin meeting chose to approach the deliberations totally focused on this dimension. We are convinced that the framework, if it is to be successful, must also consider actions that may rest with member states or other parties or entities, though clearly the 'subsidiarity' of health matters within the EU must be recognised when developing policy recommendations.

Approach used

This report takes as its basis the discussions at the Dublin Conference as well as comments received after the circulation of the draft report to those who participated in TIP-2, together with consistent views previously expressed at the earlier Expert Panels and other relevant conferences. Initial drafts of the EU Framework for Action have been circulated to members of an Advisory Board, as well as being presented for discussions in June 2004 at the Centre for Health and Ethics in Society (CHES) at the Madariaga Foundation in Brussels, where very helpful comments and suggestions were received.

Acknowledgements

Support for the project and most of its dissemination comes from Johnson & Johnson Europe, a global pharmaceutical company. The Nuffield Trust, a UK charity for research and policy studies in health services is also supporting the report's dissemination. The CUH team is grateful to Johnson & Johnson, particularly Vice President Scott Ratzan, MD, MPH, for the unrestricted research grant, its assistance with the logistics of organising the Dublin Conference, and its scrupulous observation of the independence of the entire research effort. We are thankful also to the Nuffield Trust for its ongoing support in the dissemination of the results of this project.

The CUH team also expresses its gratitude to all the attendees at the Dublin Conference, the members of the Advisory Board, and the attendees at the CHES meeting for the significant contribution of their valuable time and expertise in the support of this project and its aims. However, all responsibility for the accuracy of materials in this document rests with the two principals, Prof. Don Detmer and Peter Singleton.

Cambridge University Health also wishes to thank those who were unable to come to the meeting, but who contributed by submitting their opinions and/or finding a replacement from within their own organisation. Trinity College Dublin and, in particular its Vice-Provost, Professor Jane Grimson, deserves praise and appreciation for gracious hospitality and support in organising this conference thereby making it an enjoyable success.

Our thanks also goes to Jane Ewart and Jackie Peeters for their work in the conference organisation and logistics, and to Christine Marking, whose general support was invaluable.

Limitations

As noted above, all responsibility for the accuracy of materials in this document rests with the CUH team: Professor Don Detmer and Peter Singleton.

Initiatives in this area, in Europe and globally are developing all the time, so that this report necessarily only shows a 'snapshot' of the current state of play and a partial one at best. Since so much more work will need to be done to take the vision of The EU Framework for Action forward into policy and practice, Cambridge University Health and the new Johnson & Johnson Centre for Advancing Health Information will remain committed to this line of research since it is so important to the future of health care.

We must acknowledge that the outcome of this study may have been affected by the decision to conduct the meetings in only the English language. This may have limited those choosing to participate and certainly it has limited the range of materials described as being available across Europe. Further, there is a clear under-representation of experts from southern and eastern member states generally, and at the Dublin conference in particular, fewer patient groups participated than we had intended. We hope that these limitations can be mitigated in future work.

Background to this Report

The first study, TIP-1 – The Informed Patient, began in late 2002 when CUH convened a series of workshops in Brussels to explore issues and current thinking, culminating in the 'The Informed Patient' conference in Cambridge, UK, in December 2002 which developed a consensus statement about four main themes:

- Create a Framework for the Future: Convene key stakeholders in the near future to develop the set of initiatives outlined in the Consensus Statement from the December 2002 conference;
- Support Implementation: Focus the EU and member state governments and the private sector explicitly on accessibility, availability, and quality of structured information for patients/citizens;
- Co-ordinate the Suppliers of Information: Develop and agree standards to promote the effective provision of quality information;
- Leadership and Education: Provide critical support to patient health education and continued professional development.

From these discussions, the first report, TIP-1: 'Informed Patient', was released in May 2003 and launched at events in London and Brussels. It provided a review of the evidence about the effectiveness of information provision to patients, and how such information could affect patients and their healthcare.

An electronic copy of the report is at: www.jims.cam.ac.uk/research/health/tip/pdf/crstudy.pdf

The results of the study were also presented at conferences during 2003 in London, Glasgow, Rome, Vienna, and Florence.

At the time of the deliberations at the Cambridge conference, it was anticipated that an existing body such as the G10 Medicines Working Group would take forward the development of the first theme, e.g. the EU Framework. However, as this topic crosses a number of EU organisational boundaries, it had not been taken up and co-ordinated by any specific body by the beginning of 2004, even though there are a significant number of initiatives that relate to and support the recommendations of TIP-1.

In order to move the agenda forward without further delay, a second conference and report, TIP-2, was organised and held in Dublin on 17th & 18th February 2004. The meeting was entitled 'The Informed Patient: an EU Framework for Action', which included representatives from policy-making bodies in Europe and beyond (see p32 for a list of participants).

6 TIP-2: The Dublin Conference – February 2004

Main conclusion

The major conclusion from the TIP-1 and TIP-2 conferences is the conviction that the future of health care in Europe demands for patients and citizens far greater 1) health-related information and 2) more active involvement in their health and healthcare. The information and knowledge support must be available at the level of the EU/member states and also at regional/local levels to assure sufficient education and support. To be perfectly clear, a policy strategy that focuses solely at the EU or member state level will be inherently unsuccessful.

Main Objective of the Dublin Conference: an EU Framework for Action

The previous conference at Cambridge in December 2002, TIP-1, established policy objectives for meeting the information needs of healthcare in Europe. The Dublin conference and its report, TIP-2, considered the need for a more concrete 'Framework for Action', detailing more specific initiatives that can be undertaken within Europe, either by EU agencies, national governments, or other parties.

The discussions were wide and varied, and formed the basis for the CUH team to develop the suggested 'EU Framework for Action'. These notes provide some insight into the thinking behind the Framework and the input of the delegates at the conference.

It is anticipated that this initial effort at an action plan will be refined and reworked as it moves into more general circulation and benefits from a wider dialogue.

Conference Considerations

The main considerations from the conference discussions were:

- Formal Promotion of the issue of health information for patients and citizens within the general public and at key policy jurisdictions is essential. This is felt to be a central, if not the central, issue and it is believed that this will require additional time to develop sufficient attention, despite the strong indications that it is gaining prominence;
- Engagement with Accession countries must receive prompt attention. The EU is changing through enlargement, and this new reality is an opportunity for the EU Framework to incorporate TIP more widely and multilaterally;
- Educational efforts need much more specific focus. These efforts must include: 1) better interpersonal and communication skills curricula for entry level and practicing health professionals, 2) better materials, including decision-support, for patients and informal care-givers, and 3) educational efforts for the general public to assure a greater understand of how to live better and stay healthier, to engage more intelligently with local health services, and to involve themselves more intelligently in managing their own care needs;
- A targeted Public Information development and deployment strategy is needed. An action plan must be developed that identifies the appropriate information that patients need, which offers relevant information over the 'patient journey', and is culturally sensitive to all key demographic segments of the population;
- A media strategy must be developed and pursued since better media relations are essential. Working more closely with the media on an ongoing basis is essential to develop a better understanding on both sides and also to promote a more responsible and educated approach to discussion of public health topics;
- Barriers and Incentives relating Public-Private Partnerships must be examined. There are major areas where both public and commercial interests coincide. Identifying incentives that will foster joint initiatives to promote key topics is advisable and an examination of current barriers is needed so those amenable to change are addressed;

- Re-package the evidence on what works. Local experimentation is quite common and often very successful, but collecting these experiences and evaluating them is inadequate today. Such evidence needs to be collected, collated, and disseminated more widely;
- Trust, Integrity, and Community requires on-going support. Supply of evidence-based, timely, relevant information to patients will support professional integrity and enhance trust by the public in their carers. Organised efforts to create greater transparency is needed to foster trust between clinicians and patients and their caregivers, e.g., family and friends. An over-emphasis on privacy considerations carries a cost in social trust and access to the information needed for system evaluation and medical progress.

The conference delegates discussed a number of aspects of the above points in greater detail and these considerations follow. It is also clear from the excellent presentations delivered at the conference and from other sources as well that much is going on within Europe. Some of the relevant initiatives are detailed in the next section.

The summary points presented above arose from the discussions in workgroup sessions that discussed a number of 'strawman proposals' put forward by the CUH team prior to the conference. The results of workgroup sessions were reported back to the conference in plenary session for discussion, and, after collation into common themes, further discussed in plenary as a suitable basis for a Framework for Action.

Promote the importance of 'Sound Health Information'

The consensus of the discussion is to link the current EU initiatives underway while maintaining a 'watching brief' on new issues as they arise. While there are strong indications that availability and proper use of evidence-based information is gaining prominence, awareness remains very important issue in its own right. A key priority of The Informed Patient project is to raise the level of awareness, but TIP is just one of a number of valuable efforts underway.

It was felt at the conference that the issue might need to be linked to 'hot topics' that had currency, both amongst policy-makers and the media. One example mentioned was the matter of patient and professional mobility, especially with the recent growth in the number of member states. Patients deserve to know where and how to seek healthcare both inside and outside their home country, and to understand the issues and risks involved.

Another potential issue that was raised was the matter of preventable errors as noted in the Institute of Medicine report: *To Err is Human*. While this is a 'hot topic', there was concern expressed that if it were not managed carefully, patients make take the information 'out of context' and decide to avoid seeking care.

Without a programme up and running, potential opportunities may come and go before a sensible approach can be developed. For example, the SARS infection could have been a suitable topic for discussing effectively informing people on the issue of risk, but such an effort today would not be likely to be considered 'newsworthy' by the media at this time.

Recommendations:

- Assure that organisations coordinate their efforts and are aware of what others are doing so overlap is reduced and coverage of all needed dimensions is assured.

It is too easy for projects to be initiated as part of a common programme, but without close co-ordination of their delivery and outputs, the overall objectives of the programme may fail or the benefits sought not be realised, especially when they are managed by different agencies.

This requires co-ordination within the European Commission as well as integration with external actions and activities in other global, European, and national bodies through a 'knowledge network' to share experience and information.

➤ **Raise the profile of the issue through suitable 'award' schemes and/or 'European Days'**

The conference felt that it was important to highlight good practice. An 'award' scheme could give a platform for promoting the issue and disseminating good practice and also encourage individuals and organisations to come forward and share their models of good practice. A specific example mentioned was the British Medical Association (BMA) Patient Information Awards³, though it was noted that it had a low-profile presence even on the BMA web-site.

The World Health Organisation have used 'World Days' (e.g. World No-Tobacco Day) to publicise and promote health issues, as well as educate the public about health risks and what they can do to counter them.

An equivalent 'European Day' focused on a key topics relevant to patient information could be an effective catalyst to capture initial attention. An 'Ask about Medicines' week in the UK was run by the British Medical Association to encourage the public to understand better the drugs they were taking.

➤ **Promote good communications practice**

It was felt that, while health correspondents were generally conscious of their responsibilities to the public, there were grounds for concern about the appropriateness of coverage of high-profile topics with over-enthusiasm for 'miracle cancer cures' and poor presentation of risks (e.g. nvCJD, MMR, or HRT treatments). It was asserted that such reporting could encourage patients to opt out of treatment and so incur greater risks from their condition.

The problems of miscommunication also appeared in healthcare with clinicians often communicating poorly through lack of time or limited appreciation for the consequences of failing to communicate effectively (e.g. poor adherence to drug regimens). The proper tools to support clinicians could help.

Mention was made of the European Health Communication Network's guidelines for health communication, which could serve to raise the issue and support a change in working habits and attitudes.

Engage with Accession countries:

The enlargement of the EU offers an opportunity to promote TIP more widely. The new accession countries will be working to meet EU standards and these efforts may foster a greater receptivity to new approaches including the establishment of good practices that may have been lacking. It was considered possible that citizens of accession countries might seek treatment elsewhere in the EU, though the process was unlikely to be one-way as there is already significant 'health tourism' as EU citizens seek cheaper private healthcare in accession countries.

It was also noted that new Commissioners after enlargement would be reviewing the EC strategies, and that this was an opportunity to raise the TIP issue as a possible approach in resolving some of the future healthcare issues (e.g. increasing pressure on healthcare budgets in face of aging populations and rising levels of chronic care).

Recommendations:

➤ **Co-operative partnerships amongst existing states and accession countries should be actively pursued.**

Co-operative initiatives begun today offer the potential to actively share and consider good practices in patient information provision. A creative mix of participant countries (or as few as two working together), would allow 'leaders' in good practice to codify practice and ensure more complete use through the various healthcare systems of the group. 'Apprentice' countries can adapt these experiences and customise procedures to meet needs of their localities.

Particularly in aspects of patient mobility, possible exchanges of patients for mutual benefit can be planned, together with supporting documentation on both sides to allow ready access to appropriate care, and to encourage new ways of working in both countries.

³ See www.bma.org/ap.nsf/Content/LIBBMAPatientInformationAward for more details

Improve Education:

This applies not only to education of professionals about communication skills and the needs of patients as noted in the first conference, but also of the public more widely to understand how to engage with their health service and to stay healthy in the first place;

Recommendations:

- Include identification of patient needs in medical and other health professions curricula
Health professionals during their formative years of education need to gain understanding of the scientific basis of effective communications and to receive training to assure that they will have the skills they need to inform patients effectively. This should include how to present technical information (including risk) in readily understandable language.
- Education in schools to promote empowerment and better use of healthcare services
This was felt to be an important part of developing basic 'life skills' in order to be an 'active citizen', though without seeking to develop a 'model citizen'. An understanding of health issues generally, and how to access health services could be critical in limiting illness and supporting efficient and effective use of health budgets to avoid waste and ensure that care is sought on a timely basis.
- Written information to accompany diagnosis
Information should explain disease(s) in the effects and likely impact on a patient and their family where such facts are known. The likely course of the malady and its treatment or treatment options should be included to prepare the patient and their family for what may come.
It should critically provide information as to where or how to seek further support including additional information, as it is needed. It was considered more desirable for key information to be imparted to the majority of patients rather than offering only a few a detailed technical compendium.

The Expert Patient: Getting patient to help train doctors

From '*Telling it as it is*' by Dr. Pippa Keech in BMJ April 2004

The patient, an elderly lady dressed only in her underwear and petticoat, stands mutely beside our lecturer as he tells us, third-year medical students, about her disease. He leads her along the lecture platform, demonstrating her abnormal gait, and turns her away from us and gets her to flex her spine so that we can see how it curves abnormally.

Move forward 15 years to an arthritis management day. This time our patient introduces herself as she sits among our small group of doctors. She is a "patient-partner," trained by the drug company, Pfizer, to show us how to examine knees affected by rheumatoid arthritis—her knees. She does this confidently and competently, and, while doing so, she relays how these joint changes have affected her personally. As her severely rheumatoid hands are useless, an adequate range of movement in just one of her knees means that she can still get out of the chair without help. The joint effusion she shows us means that she has to work extra hard to maintain the necessary flexibility, but for her this is independence, so she works at it with dogged determination.

A teenager who had to sell her beloved horse, a young adult unable to pursue her chosen career in nursing, a mother unable to hold or breast feed her baby—we hear how the disease has altered the course of her life utterly. Her role as a patient-partner is highly informative for me and empowering for her. Initially, I was shocked to hear a patient talking so knowledgeably about her condition, and then ashamed of that shock. My medical student training all those years ago is obviously more ingrained than I realised. While I embrace the idea of sharing care with a patient in a general practice setting, I am obviously just not used to the idea in a teaching setting.

It has taken me 10 years of general practice to see patients as people and not as diseases. Patient-partners, while obviously better suited to teaching about some diseases than others, seem a good way of imbuing budding doctors with this knowledge a lot earlier in their careers.

Pippa Keech General Practitioner, Forestside Practice, Marchwood, Southampton

➤ **Ensure doctors provide links to other useful sources of information**

Examples of such relevant sources are patient organisations and social services. Overcoming the reluctance of doctors to provide such information based upon their concerns about the quality of the information delivered and either actual or perceived liability of legal exposure from any harm coming from such secondary advice was expressed. If the links were vetted and approved by healthcare systems or payers, such issues might be minimised.

➤ **Fact sheets for doctors for information in lay language**

Implementation of the previous two recommendations will be simplified through the ready provision of prepared information for doctors to provide to patients (perhaps through a computer-based decision-support system, such as PRODIGY⁴ used in the UK). This ensures quality and consistency of the information provided, shares the cost of providing information, and reduces the barriers to adoption of good practice. The InfoPark project is a good exemplar of how to do this.

➤ **Support messages with pictures (e.g. 'risk ladder')**

Generally, there has been a tendency to make patient information leaflets (both those provided with medicines and in healthcare) text-dominated if not text-only. This deters even the most literate and presents major barriers for those less adept at reading.

Pictures may make a significant difference to readability and engagement by signalling that the information is accessible. Further, pictures may offer a broad concept of what the accompanying text will involve.

➤ **Improve readability of patient information leaflets (EMEA)**

This is a specific action recommended with respect to patient leaflets and the European Medicines Evaluation Agency (EMEA) that regulates such materials. While it is recognised that the EMEA is working in this area and that this need had been recognised by the G10 Committee, conference participants felt that the primary purpose of these leaflets to inform the public can get lost and rendered self-defeating by attempting to be 'all things to all people'. That is, seeking to develop a 'one size fits all' document is flawed. Instead, rather than cramming too much information into a single leaflet, the leaflet should direct the interested reader as the person's understanding matures to sources offering further details, including their physician or pharmacist.

The 'Expert Patient' – different interpretations

This can mean a simple appreciation that patients have their own corpus of knowledge. It is important that doctors recognise that patients often understand their bodies well, if not in the same scientific sense that doctors do. Only patients can understand how a condition and possible treatments may affect their lives and those of their family – unless the physician takes the time to find out. Given the patient will be the one to experience the condition and treatments, it is vital that their 'expertise' in their own lives is recognised and respected.

It is important that clinicians and healthcare managers recognise that patients experience first-hand the treatment they receive in a way that no member of the clinical team does. They will endure the waiting and delays that healthcare systems can impose on them; they often see the obvious and simple ways in which the care could be delivered more easily and appropriately – if only someone took the trouble to ask and tap into this 'expertise'. The commercial sector has long understood the need to understand their customer – if only healthcare systems sought to do the same.

Patients, with appropriate support and training can be very effective in helping to train clinical staff in understanding the patient perspective, and to learn to treat patients as the people they are not the disease or condition they have. A real-life story simply expressed by a patient can be a far more effective form of instruction than an academic lesson about communicating with patients.

Patients who have experienced a chronic condition for some time, will have learnt a range of coping mechanisms. Learning these from a peer can be far more effective than being told by a clinician who may have no personal experience of living with a disease. Being involved in helping others in their own self-management can be very beneficial for the expert patient themselves in psychological terms. Using such 'expert patients' may release healthcare staff for other duties and so be economically beneficial – this can be viewed pejoratively as exploiting patients instead of paying staff, but if correctly done can be good for all concerned.

⁴ www.prodigy.nhs.uk/PILs/index.asp

Public Information Development and Deployment Strategy:

Identify the information that is appropriate, as the patient needs it and as their 'patient journey' evolves. To meet the needs of all patients, it must reflect different segments of the population, e.g., languages, ethnic sub-populations, etc.

Recommendations:

➤ Develop model of how patients information needs vary

An literature review research project would allow an initial model to be developed of how patient information needs vary by:

- Population segment
- Age/generation
- Education/learning difficulties
- Gender
- Culture/Ethnicity
- Language
- Stage of disease or condition/progress through the 'patient journey'

This model could then be used to guide improved patient information, which would be evaluated in practice for effectiveness and relevance. The key aspect is that it should move current practice away from providing a single 'information leaflet' for all members of the population to a wider and staged delivery of information and knowledge suited to patient needs as they develop over time.

Develop better media relations:

This not only involves working with the media on an ongoing basis to develop a better understanding on both sides, but also to promote a more responsible and educated approach to discussion of public health topics;

Recommendations:

➤ Develop European Health Media Network

This should involve initial 'focus group' meeting with health correspondents across Europe and market segments to assess how best such an initiative could be developed, and the practicalities of engaging media channels and journalists to improve the information and education of the public in health matters.

➤ Develop and promote good practice guidelines for communicating health risks

There have been a number of studies in this area, both generally and specifically in health, identifying guidelines and how individuals seem to process risk information.

This may need to be 'repackaged' into an appropriate form to be presented to the media, along with vignettes or case studies to illustrate the dangers of incorrect or inappropriate media communications.

Explore Public-Private Partnerships:

There are areas where both public and commercial interests can coincide to provide funding for initiatives to promote more widely key topics and better understanding of health issues amongst the public.

Recommendations:

➤ Identify areas where a public health campaign could jointly benefit patients, industry, and the healthcare system

By making the public much more aware of certain conditions, they may adopt lifestyle changes that reduce or essentially eliminate the risk of developing a condition; they may be made aware of self-treatment options or self-management to improve their control of a disease; or, they may know enough to visit their doctor sooner for less intensive treatment before severe debilitation occurs. All of these actions will take pressure off the healthcare system.

Any public health campaign that in a simple 'blanket' manner encourages patients to seek advice from doctors is likely to lead to a short-term increase in demand. Indeed, this is reported to be one of the main reasons direct-to-consumer advertising (DTCA) has been banned in Europe. However, if real education occurs, any short-term increase in demand is likely to be followed by reduced long-term demand or by lower cost of intervention overall, and a campaign would be a positive strategic option. The financing challenge is to underwrite a solid public health campaign and also deal with the short-term increase in treatment costs from a public healthcare system that is usually strapped for cash.

For industry, the attraction of public campaigns for a specific medication or problem requiring a 'pill' for treatment is the prospect that it will result in increased sales. Of course, effective preventative measures reduce overall demand in the longer term.

A joint campaign by industry and government that targets certain populations for a pro-active well-designed programme of information and treatment targeted at specific conditions may be both health enhancing and cost-effective. Careful co-ordination will be needed to ensure that there is meaningful impact without destabilising the healthcare system.

An opportunity for public-private partnership (PPP)

The G10 Committee and DG Enterprise have long spoken of the need for 'public-private partnership' to move forward the agenda for better information provision about medicines to patients and the public.

Many public health campaigns have focused on promoting healthy lifestyles (e.g. taking exercise or the 'five-a-day' nutrition campaign) or avoiding negative factors (such as smoking, excess alcohol, unsafe sex). These have rarely been wholly successful, partly through the difficulty of working against people's natural inclinations, partly because of limited funding (which may limit the range and extent of a campaign).

The pharmaceutical industry has not always been successful in its promotion activities, mainly because of regulatory restrictions, but also poor or inappropriate targeting.

One campaign that has been successful is an 'educational' campaign run by Novartis concerning 'nail fungus', Onychomycosis. The promotion is permitted as there is no mention of any branded medicine, though Novartis is one of the few suppliers of an appropriate medication, so is bound to benefit from increased demand.

When the campaign was run in the Netherlands, visits to GPs went from an average of 2 per month per GP to 20 per week, resulting in the campaign being condemned by the Dutch clinicians association, NHG. This has often been quoted as an example of the abuse of the advertising regulation.

The point of this example is that a simple campaign may have dramatically changed the personal lives of people who simply thought that they had ugly toes – and who might have gladly paid for treatment if they only knew that it was a medical condition, not a quirk of fate. The fact that nail fungus can often occur in diabetics may also mean that a number of diabetes cases could have been diagnosed and treated earlier because of the health promotion campaign.

Better would be for a cooperative campaign, ensuring that the healthcare system was properly prepared for a rise in enquiries from patients, and that doctors were properly briefed as to the appropriate course of action.

Re-package the evidence:

There is much local experimentation that shows clearly that information can be improved to promote better health and healthcare. This evidence needs to be collected, collated, and disseminated more widely if it is to have a real impact.

Recommendations:

- Develop network of centres across Europe

This should link national networks into a pan-Europe network.

National networks should permit close collaboration on materials which will be effective within a particular healthcare system, as well as instigating dissemination activities to a specific healthcare economy using appropriate methods and recognising local incentives and/or barriers to adoption.

A pan-European network could provide common infrastructure to support national networks as well as allowing generalisable 'good practice' to be generated and shared. There is the possibility that general treatment or disease materials could be shared for those speaking less frequently encountered languages. Approaching this challenge simply on a state-by-state basis would be more expensive and, indeed, a collaboration might be the only way a particular health economy may invest in such interventions.

The network could also co-ordinate the information necessary at a European-level to manage to patient and professional mobility.

Support Trust, Integrity, and Community:

It is important that the provision of better information to patients is done to support the trust by the public in their carers – greater transparency should help to foster rather than reduce trust.

There was a concern that some information poorly or incorrectly presented could have adverse effects. Clinical performance statistics, which do not reflect case-mix aspects appropriately, may cause patients unnecessary concern and/or lead to incorrect choices (e.g. refusing treatment by those doctors with best practical experience, but apparently poor performance by choosing to treat patients at advanced stages of a conditions with lower likelihood of a positive outcome).

However, this requires balanced judgement and a risk of poor interpretation should not be used as an excuse not to provide relevant information to patients. Evidence suggests that the public is quite good at discriminating between good and bad information, though its trust in some media channels may be misplaced (e.g. effects of media misinformation on MMR risks).

Recommendations:

- Ensure that emphasis is on improving information provision and communication rather than simply criticising the current situation

It is important to emphasise the positive and to provide positive support and incentives to the adoption of new ways of working by providing tools and training to ease the transition.

- Ensure that professional and organisational cultures recognise the change in public expectations
- While the move towards 'consumerism' and the emphasis on individual 'rights' is far from uniform across Europe, it is clear that this change is reflected across all countries, though modified by local conditions.

It is critical that trust in healthcare providers, individuals as well as organisations, is supported by transparency and inclusiveness.

This clearly ties in with the recommendation on education in communication skills, but needs to be promoted from the top by example and leadership

Membership of Dublin Conference

Name	Title	Organisation
Dr. Franklin Apfel	Policy Consultant	
Philip Berman	Director	EHMA – European Health Management Association
Michel Bourges-Maunoury	Secrétaire Général	Madariaga European Foundation
Minister Ivor Callely	Minister of State	Department of Health and Children
Karen Comte	EU Affairs Adviser	European Group of Television Advertising
James Copping	DG for Enterprise	European Commission
Prof. Don Detmer	Research Director	Johnson & Johnson Centre for Advancing Health Information
Dr. Luisa Dillner	Head of BMJ Learning	British Medical Journal
Dr. Joanne Epping-Jordan	Coordinator, Health Care for Chronic Conditions (CCH)	WHO – World Health Organisation
Bob Gann	Director	NHS Direct Online
Jean Georges	Secretary General	Alzheimer Europe
Prof. Pierangelo Geppetti	Professor of Clinical Pharmacology	University of Florence
Alastair Graham	Management Consultant	Eastern Regional Health Board
Prof. Jane Grimson	Vice Provost	Trinity College Dublin
Gill Gyte	Representative	Cochrane Collaboration Consumer Network
Christine Hancock	President	International Council of Nurses
Jean-Claude Healy	Head of Unit	European Commission (DG Information Society)
Dr. Delon Human	Secretary-General & CEO	The World Medical Association
Horst Kloppenburg	Principal Administrator, Unit C2	Directorate General for Health & Consumer Protection, European Commission
Dr. Roland Lemye	Vice-President	CPME – Comité Permanent des Médecins Européens
Christine Marking	EU Health Policy Advisor	
Stephen McMahon	President	Irish Patients Association
Isabelle Moulon	Head of Safety & Efficiency of Medicines	EMA – European Medicines Evaluation Agency
Anne Nolan	Chief Executive	Irish Pharmaceutical Healthcare Association
Dr. Anne Papin-di Pompeo		Johnson & Johnson
Chantal Porges	Communication Director	Eucomed – The European Medical Technology Industry Association
Andreas Preising	Manager Government Affairs	European Federation of Pharmaceutical Industries and Associations (EFPIA)
Dr. Scott Ratzan	Vice President Government Affairs, Europe	Johnson & Johnson
Mel Read	MEP	European Parliament
Michael Rogers	Policy Adviser	European Commission
Peter Singleton	Senior Associate	Cambridge University Health
Diane Whitehouse	Scientific Officer	European Commission (DG Information Society)
Raymond Smyth	Assistant Principal	Irish Department of Health and Children

Table 1- TIP 2004 Dublin Conference attendees

7 Current activities and initiatives

A number of initiatives have appeared (or developed further) since the last report in May 2003, and many of these were presented or referenced at the Dublin conference. These are grouped by the main funding agency (where appropriate):

European Medicines Evaluation Agency

— EMEA/CPMP Working Group with Patients Organisations

This Working Group established in 2002 to involve Patient groups in the operations of the EMEA. It works as three sub-groups on Transparency/Dissemination; Product Information; and Pharmacovigilance. It has recently (April 2004) produced a document, *Recommendations and Proposals for Action*⁵. The range of recommendations is too long to reproduce here, but they did address issues around 'Transparency and public communication' and 'Education campaigns ... towards healthcare professionals'.

— Co-ordination of Pharmacovigilance data across Europe

EudraVigilance is one of the main pillars in the EU Risk Management Strategy in pharmacovigilance. It aims to provide detailed and consistent data for all medicinal products authorised in the Community, as well as to support efficient communication of safety issues and alerting mechanisms to the relevant authorities, industry, health care professionals and the general public. It is managed and funded by EMEA.

— Information on Clinical Trials

EudraCT is a database of all clinical trials commencing in the Community from 1 May 2004 onwards. It has been established in accordance with Directive 2001/20/EC.

CancerBACUP also hosts a database on cancer research trials available to patients in the UK and Europe, based in part on a database created by European Organisation for Research and Treatment of Cancer (EORTC).

These will allow patients to find trials for new drugs which may their only hope of cure.

European Commission DG Enterprise

— G10 Communication (1st July 2003):

This communication⁶ was the official response to the G10 Report⁷ of May 2002. Pertinent recommendations were:

- *Enhanced Information for patients* (Recommendation 10), including establishment of working group to review existing information
- *Patient Information Leaflets to be improved and to involve users* (Recommendation 11)
- *Funding of Patient Organisations* (Recommendation 13)
- *Consideration of Enlargement* (Recommendation 14) including impact on other areas

— G10 Public Forum – 3rd June 2004

Run in conjunction with DG Sanco, this meeting addressed: 'A Stronger European-based Pharmaceutical Industry for the Benefit of The Patient', the sub-title to its communication (see above). This may be the first stage of their commitment to 'explore, with stakeholders, a range of approaches to provide a realistic and practical framework for the provision of information on prescription and non-prescription medicines.'

— DG Enterprise/Sanco Working Group on Patient Information

This working group is due to be set up in 2004 to take forward the G10 recommendations and the request of the European Parliament to consider this area in more detail.

⁵ Available at www.emea.eu.int

⁶ Available at http://pharmacos.eudra.org/F3/g10/docs/G10_CommComm_EN.pdf

⁷ Available at <http://pharmacos.eudra.org/F3/g10/docs/G10-Medicines.pdf>

European Commission DG Sanco

- DG Enterprise/Sanco Working Group on Patient Information
(See DG Enterprise above for detail)

- DG Sanco/InfSo European Health Portal

This is part of a wider initiative on health information and knowledge management. A Global Implementation Plan⁸ was published on 5th May 2004. It seems to focus mainly on supporting communicable disease reporting, though it notes under 'Benefits for citizens/enterprises':
Improvement of information for patients and health professionals about the acquisition and knowledge generated at Community level available from a trustworthy and recognised source. On the longer term an impact on the health of citizens is expected through better information and influence on lifestyles and health determinants.'

- European Patients Forum (EPF)

This pan-European patients group is to be funded by the European Commission to provide a voice at the EU-level for patients. There are restrictions on patient organisations which can join the EPF in terms of accountability and representation. For more detail see their web-site: www.europeanpatientsforum.org

- European Public Health Alliance (EPHA)

The European Public Health Alliance (EPHA) represents over 90 non-governmental and other not-for-profit organisations working in support of health in Europe. It has been existence for over 10 years. Its brief excludes governments and industry.

EPHA has a number of aims, which includes: '*maximising the flow of information concerning health promotion and public health policy developments*'. Its activities focus around news, conferences, such as Health Intergroup of the European Parliament, and a very effective web-site with links to relevant documents. It focuses on EU policy rather than information practice.

EPHA receives funding from the European Commission, from membership fees and from subscriptions to our publications.

EPHA is the content partner of the European Internet portal, www.EurActiv.com

- European Health Policy Forum (EHPF)

This is not to be confused with the European Health Forum Gastein (EHFG which is an annual health conference held in Bad Gastein). It is part of the European Health Forum initiative, which consists of an 'Open Forum', a 'Health Policy Forum', and a 'Virtual Forum'.

The first meeting of the Open Forum was on 17th May 2004 on 'Health in an Enlarged Europe'.

The EU Health Policy Forum meets twice a year in Brussels, normally in June and in December, having first met in November 2001, and brings together umbrella organisations representing stakeholders in the health sector. In December 2003 it produced a document '*Recommendations on Health and EU Social Policy*', where it noted '*the positive economic contribution of health promotion strategies*'.

The Virtual Forum is yet to start and is presumed to be closely linked with the progress of the European Health Portal.

- High-level reflection process on patient mobility and health care developments

This was instigated by the Health Council in June 2002. After a series of meetings, a report agreed at final meeting in December 2003 made nineteen recommendations across five main areas:

- *European cooperation to enable better use of resources*, covering issues such as the rights and duties of patients; activities to facilitate the sharing of potential spare capacity; facilitating cooperation in border regions; European centres of reference; and the evaluation of medical technology.
- *Information for patients, professionals and providers*, covering issues including a strategic framework for information initiatives covering issues such as health policies, health systems, health surveillance, technological solutions, quality assurance, privacy, records management, freedom of information and data protection.

⁸ Available at europa.eu.int/comm/health/ph_information/documents/ev20040705_rd03_en.pdf

- *Access to and quality of care*, covering issues such as improving knowledge on access and quality issues and analysing the impact of European activities on access and quality.
- *Reconciling national objectives with European obligations*, covering issues such as improving legal certainty and developing a permanent mechanism to support European cooperation in the field of health care and to monitor the impact of the EU on health systems.
- *Health and the Union's cohesion and structural funds*, looking at how to facilitate the inclusion of investment in health, health infrastructure development and skills development as priority areas for funding under Community financial instruments.

A European Commission Communication in response was published in April 2004⁹.

— **HP-source.net – to promote sharing of experience in health promotion**

This initiative, which was funded by DG Sanco up to December 2003, was launched in November 2003. It is now funded by its member organisations.

— **European Public Health Information Network (EUPHIN)**

This is intended to be a structured and comprehensive Community system for sharing, exchanging and disseminating information within the public health area. It is a physical 'telematic' rather than a social network, covering a health monitoring application (EUPHIN-HIEMS), a health surveillance application for communicable diseases (EUPHIN-HSSCD), a blood transfusion chain application (EUPHIN-BLOOD), an injury data application (EUPHIN-INJURY) integrating, in particular the home and leisure, an accidents database (EHLASS), and an application for the collection of data and information on rare diseases.

It is supported by DG Sanco, DG Enterprise, WHO, OECD, as well as countries within the EEA (European Economic Area).

This could be used to provide a physical infrastructure for linking national TIP networks or providing a central TIP database of good practice and related evidence.

— **Network of Competent Authorities (NCA) in Health Information**

Run under the aegis of DG Sanco, the Network of Competent Authorities has been established with representatives of health ministries and institutes. It meets twice a year and monitors and advises on implementing the information strand of the EU Public Health Programme 2003–2008. It has seven working parties deal with health information priority topics: indicators, environment and health, mental health, accidents and injuries, lifestyles, mortality and morbidity, and health systems. They meet twice a year.

One of its stated objectives is '*Improving information to the citizen and to policy makers by means of reports and the internet*'. However, the emphasis seems to be more on 'information' as statistics about the state of health of the public rather than information for the public or information about the effectiveness of the healthcare systems in Europe.

— **Health Evidence Network (HEN) with WHO**

HEN is an information service primarily for public health and health care decision-makers in the WHO European Region. It aims to provide easy access to sources of evidence as well as summary answers to specific questions. It comprises two services: a form of 'frequently asked questions'; and information on and links to sources of evidence such as databases, documents and networks of experts, e.g. Cochrane Collaboration.

As such it may be a useful channel for distributing evidence and materials concerning TIP best practice, rather than acting as infrastructure. It may also be a useful location to recruit partners who may visit the HEN web-site.

— **European Public Health Information, Knowledge and Management System (EUPHIX)**

It is run by National Institute for Public Health and the Environment in the Netherlands. Together with Health Evidence Network (HEN) with WHO, it is expected to work on large scale networking and linking of health information sources in EU. Very little detail seems to be publicly available.

⁹ Available at http://europa.eu.int/eur-lex/en/com/cnc/2004/com2004_0301en01.pdf

— EC Working Group on Healthy Lifestyles

The European Commission is to establish a Working Group on Healthy Lifestyles which will, with the participation of Member State experts, contribute to improving the collection and diffusion of data, information and knowledge about healthy lifestyles.

European Commission DG InfSo

— eHealth Communication – Action Plan to improve health not just healthcare

On 30th April 2004, DG InfSo released its action plan, entitled 'e-Health: making healthcare better for European citizens: An action plan for a European e-Health Area. This document details the European Commission's strategy for e-Health for the next five six years.¹⁰ It focuses on citizen-centred health and on improving access, quality, and economy of health systems through eHealth applications. The Communication was presented to the Council on 2nd June 2004.

— eEurope eHealth Awards

These awards for good practice in eHealth applications have been awarded since 2003 to demonstrate possible uses of communications technologies and to encourage uptake of similar practice elsewhere in Europe. Further information is available at www.e-europeawards.org.

— Health Information Network Europe (HINE)

This 'public private partnership' is mainly concerned about the adoption of information and communications technologies (ICT) within Europe and is jointly funded by the European Commission and commercial subscribers. While the content may not be directly relevant to patient information provision, the approach may be one that could be replicated to support a European network for best practice and evidence.

— Other health information projects

DG Infso has also funded projects explicitly aimed at improving health information for patients or citizens: e.g. WOMAN II (www.womanlab.com) and WRAPIN (www.wrapin.org).

European Commission DG Education

— European Network of Health-Promoting Schools (ENHPS)¹¹

This network was created in 1992 between the Council of Europe, World Health Organisation (WHO), and the EU. An evaluation of the initiative in the Czech Republic showed that all schools who had participated in the Health Promoting Schools project for one year performed better than the new schools, through reduced absence.

ENHPS appears to have ceased major activities in 1998, though its web-site is updated. Initiatives continue in individual countries, possibly supported by informal networks.

European Commission DG Employment and Social Affairs

— European Network for Workplace Health Promotion (ENWHP)

This was established in 1996 and is supported by DG Sanco. Often Workplace Health Promotion focuses on workplace factors in preventing ill-health or accident, promoting health and safety at work, rather than a platform for promoting health generally. It provides 'good practice' case studies, such as Volkswagen AG where therapeutic support for alcoholic employees reduced absenteeism for this group by 75%.

In May 2004, ENWHP published a report, *Making the case for Workplace Health Promotion*, and in August 2004 released the ENWHP Toolbox, available at www.enwhp.org/download/report_toolbox.pdf.

¹⁰ Available at europa.eu.int/information_society/doc/qualif/health/COM_2004_0356_F_EN_ACTE.pdf

¹¹ Its web-site is <http://www.euro.who.int/ENHPS>

The Northern Ireland Health Promotion Agency (HPA) notes that promoting health in the workplace improves the working environment and is beneficial to companies and employees. It can help to:

- attract and keep the best employees;
- improve motivation, creativity and productivity of employees;
- reduce illnesses and absence rates;
- reduce the bill for work-related ill health;
- decrease the number of accidents and legal claims;
- enhance corporate image and help keep a competitive edge.

Recent campaigns include reducing violence in the workplace and smoking in the workplace – Ireland has recently banned smoking in the workplace, including pubs and restaurants. In the UK in November 2003, a health campaign, Sign-Up, was launched to improve health in the workplace (see www.signup.net).

European Commission DG Research

— InfoPark project on information about Parkinson's Disease

This project was instigated under the DG Research Framework Programme 5 (FP5) and involves institutions across 7 countries, including Estonia, Czech Republic and Slovakia from the new EU members admitted in May 2004.

It showed the value of international co-operation and sharing expertise. A consistent set of documentation was produced in seven languages, separated into materials for patients, carers, and professionals (non-PD specialists) reflecting their different interests and perspectives. The materials are available at www.infopark.uwcm.ac.uk

It is notable for its focus on producing materials to help non-specialists (lay and clinician) understand about PD and its effects. Such materials would be a suitable model for GPs to provide to patients and their carers, as well as helping them understand the probable impact of the condition on their patients – both clinically and socially.

Unfortunately, there is no follow-through funding to support wider dissemination of the principles, guidance, and exemplar materials to actually be adopted in the field.

Johnson & Johnson

— Establishment of Centre for Advancing Health Information (CAHI)

This initiative is still in its early stages of formation, involving a policy centre based at the Madariaga Foundation in Brussels (part of the College of Europe) and a Research Centre based at the Judge Institute of Management (the business school at the University of Cambridge).

The centre has helped fund this project as well as sponsoring a number of seminars in Brussels on a number of topics from information provision to patient and professional mobility.

World Health Organisation

— World Health Organization Regional Office for Europe

Includes the EuroPharm Forum linking pharmacists organisations across Europe, and EHCN (see below)

— European Health Communication Network (EHCN)

This network, set up by WHO in 1997, includes journalists, doctors, educators and advocates from NGOs. Its purpose is to bring communication professionals more centrally into the health sector, recognizing and promoting awareness of the importance of health communication, supporting skills development, and making ethically and scientifically sound health information available through the media. This information should be relevant to current health concerns, reliable and understandable by target audiences.

Unfortunately, it now appears to be dormant with the last Newsletter dated January 2002.

— European Health Communications Network – Media Guidelines

These do not actually appear on the EHCN web-site, but are available from www.presswise.org.uk/display_page.php?id=165. They are reproduced here in Appendix 1: Guidelines.

— WHO Report on Adherence

This report¹², Adherence to long-term therapies: Evidence for action, was published in January 2003, and covers issues about adherence in great detail.

International Council of Nurses

— Patient Talk (www.patienttalk.info)

This is a web-site to provide information to patients and carers across Europe. However, at present, it only provides information in English and on a limited range of topics. It is sponsored by Johnson & Johnson.

— World Health Professional Alliance (WHPA) Leadership Symposium

Rather as patient groups in Europe have been joining together to form broader based alliances, so too have professional groups. In particular, the World Medical Association (WMA), International Council of Nurses (ICN) and International Pharmaceutical Federation (FIP) have joined together in 2000 to form the WHPA. The first international meeting of nursing, medicine and pharmacy took place in Geneva in May 2004 to strengthen the bond and encourage collaboration between the three health professions at the country level.

Patient Groups

— Creation of new European-level cross-condition alliances

While the European Patients Forum, mentioned above, was supported by DG Sanco, patient groups have generally been collaborating to raise their profile in Europe (e.g. GAMIAN to bring together a wide range of different mental conditions to work more effectively in promoting mental health issues).

— European Institute of Women's Health (EIWH) statement

The EIWH produced a statement in July 2004 entitled *Women as Better Informed Patients and Carers*, addressing four main points:

- The Internet
- Improving patient information about medicines
- Health education and disease awareness campaigns

Other bodies

— European Federation of Pharmaceutical Industry Associations (EFPIA)

In June 2004, EFPIA produced a statement: *Enhancing the Provision of Health Information to Patients in Europe: a Policy Memorandum*, including six 'principles' around information to patients (see Appendix 1)¹³

Examples of National Activities

— Spirasi (Ireland)

This initiative provides health information for asylum-seekers.

— NHS Direct (UK)

At one level this can be considered a telephone triage system, but actually represents a range of new channels for information, including on-line services such as patient-entered health data (www.healthspace.nhs.uk). A detailed presentation was given by Bob Gann, NHS Direct Online, at the Dublin meeting. It was one of the winners of the eHealth 2003 awards.

¹³ Available at www.efpia.org

— **NHS Direct and BMJ/BestTreatments**

BMJ/BestTreatments is mentioned as an example of good practice in Appendix 2, providing patient-readable material from the professional evidence available from the Clinical Evidence publication. NHS Direct has just agreed to publish this material through its portal for the benefit of UK citizens.

— **Self-reporting of Adverse Drug Reactions**

NHS Direct has run a pilot system in the self-reporting of adverse drug reactions (ADRs) in London. A similar project in the Netherlands showed earlier detection as well as some previous unreported reactions. A previous study in Scotland had shown that not all patients report reactions to GPs, who also may not formally report the reaction, leading to significant under-reporting. The conclusion was that even if there were errors in taking reports from patients directly, then this might still be more accurate than the current under-reporting.

— **Commission for Patient and Public Involvement in Health (UK)**

This body was set up in January 2003. Its remit is to ensure that the public is involved in decision making about health and health services. It co-ordinated Patient and Public Involvement (PPI) Fora at local levels, and ran the Independent Complaints Advocacy Service. Having signalled a significant shift in policy, it is due to disappear in a bout of reorganisation, though it is not clear yet what will emerge in its place.

8 Recent findings

This section covers materials omitted from or published since the first TIP report.

Public use of the Internet

Nettleton et al (2004) have shown that members of the public naturally vet the information that they find on the Internet, generally recognising the dangers that poor information can pose. They perceive the potential need for information quality markers, but for other users not themselves. It is concluded that the public may not actually use information quality markers as they may consider that they are perfectly capable of distinguishing 'good' from 'bad' information. Further it is shown that the 'digital divide' is not simple, reflecting on people's own comfort with the Internet and general information-seeking behaviour, which is not necessarily correlated with ownership of home computers and communication links, as they may use public facilities or those of friends and family, or make use of other people in their search for information.

Professionals as channels for information

A UK Consumers Association study showed that information provision to patients by professionals could be very unreliable.

Elwyn et al (2003) note how doctors can fail to interact effectively with patients, and advocate a greater emphasis on 'concordance' through involving patients and gaining real agreement to the treatment proposed.

Britten (2004) notes from other studies (mainly Little (2004)) that doctors' perceptions of patients' preferences are often out of accord with the patient's actual preferences, e.g. interpreting that a patient definitely wants a prescription far more commonly than is actually the case.

Little (2004) shows that improving doctor-patient communication does not necessarily increase consultation times.

Beresford and Sloper (2000) note the difficulties that disabled young people can have gaining the relevant information, quoting *'It seems to take a lot of persuading to get doctors to tell you everything'*.

Patient-led learning for professions

While we have commented previously on initiatives, such as the UK 'Expert Patient' programme to support patients in self-management through peer education, Jones et al (2000) cover an initiative to involve patients in the education of professionals to increase their awareness and understanding of patient information needs.

Having ourselves involved patient representatives in Health Informatics courses, we can only support the idea that this can be an extremely rewarding experience for all concerned, rooting academic discussions in real-life experience, as well as providing a strong focus for learning. The only danger was that the more academic sessions of the course paled in comparison.

Involving patients in managing healthcare

Elwyn, Todd, et al (2003) interviewed a number of individuals with epilepsy in focus groups, where they articulated a need for better information, but, perhaps more importantly, indicated criticisms of their treatment and that a better service could have been provided if only their opinions and experience had been sought.

In the UK, there has been much impetus to involve patients in the management of care services, from the recruitment of members of the public to serve on the boards of Foundation Hospitals, the appointment of a Director for Patient and Public Involvement, the setting up of a Commission for the Patient and Public Involvement in Health (unfortunately, now to be abolished after 18 months) and the setting up of local Patient Fora.

The effect of the media

Harrabin (2003), reviewing effects of issues such as SARS and MMR vaccination, notes that 'journalists must continue to report new stories and hold governments to account. But it calls for more effort to put scares into context, to rein back scares before they spin out of control and to seek out fresh stories on major risks to health'.

Media Literacy

In a BBC programme, the UK Culture Secretary, Tessa Jowell, said that 'in the modern world, *media literacy* will become as important as maths or science', which raises interesting questions of public education and the appreciation that messages need careful interpretation, reflecting the interests of the source and/or channel. It echoes the suggestions from the Dublin conference of raising awareness of communication issues, both in the public and the media themselves.

Health Literacy

This term has long been used and supported by Pfizer, the pharmaceutical company, in the United States, but has recently gained prominence in the UK through a National Consumer Council survey of 2000 adults, *Health Literacy: being able to make the most of health*¹⁴, which showed up significant inequalities in terms of access to health information, even in terms of reading package insert leaflets with medicines – 27% of the higher social groups were likely to read them, but only 12% of the less well off. Not that either figure is particularly encouraging for the effectiveness of such 'patient information leaflets'.

¹⁴ Available at www.ncc.org.uk/health/health_literacy.pdf

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Macmillan Cancer Relief	www.macmillan.org.uk
EFPIA	www.efpia.org

Appendix 1 – Examples of Guidelines

People need simple and clear advice and guidelines to help them understand what they need to do and how change can be effected within the healthcare system. If only broad guidelines are given, the people may be uncertain how to start, how to plan and execute change. Toolkits to support change deserve evaluation.

An example given of a comparable guideline is the WHO 5A's model use to promote patient-centred care: Assess, Advise, Agree, Assist, Arrange. The A's are part of their wider guidance on good chronic care (see box). The A Model facilitates memory thereby making action more likely. It provides structure to patient interactions; emphasises the need for exchange of information, mutual recognition; and supports joint decision-making.

More immediately relevant guidelines suggested by the Dublin conference include:

- European Health Communication Network – 10 Ethical guidelines for journalists
- BMA (Doctor-Patient Partnership) – Questions patients should ask their doctor
- Chronic Self-Management – Kate Lorig

It was noted at the Dublin Conference that disease-specific guidelines might also be needed to support particular aspects of care. It was also commented that there was much generality in chronic care, which was often obscured through providing disease-specific literature.

Some of the guidelines mentioned are detailed below:

Quality criteria from Institute of Medicine: 'Crossing the Quality Chasm' (National Academy Press 2001):

- Safe – avoiding harm to patients from the healthcare system
- Effective – avoiding under-use and overuse
- Patient-centred – respectful and responsive to individual patient preferences
- Timely – reducing waits and potentially harmful delays
- Efficient – avoiding waste of resources
- Equitable – providing quality care irrespective of aspects, such as gender, ethnicity

Ask About Your Medicines: Doctor-Patient Partnership – May 2003

Here are some questions to ask a health professional to help you understand your medicines.

1. What does this medicine do?
2. How long will I need to use it?
3. How and when should I take it?
4. Should I avoid any other medicines, drinks, foods or activities when I am taking this medicine?
5. What are the possible side effects and what should I do and who should I tell if they happen?.

General Principles of Good Chronic Care: WHO – December 2003

These general principles of good chronic care are relevant to the management of all chronic conditions and risk factors. These principles can be used in managing many diseases or risk conditions:

1. Develop a treatment partnership with your patient.
2. Focus on your patient's concerns and priorities.
3. Use the 5 A's: Assess, Advise, Agree, Assist, Arrange.
4. Educate patient on disease and support patient self-management.
5. Organize proactive follow-up.
6. Involve "expert patients," peer educators and support staff in your health facility.
7. Link the patient to community-based resources and support.
8. Use written information—registers, Treatment Plan, treatment cards and written information for patients—to document, monitor, and remind.
9. Work as a clinical team.
10. Assure continuity of care.

Guidelines for professional health communicators: EHCN – December 2001

- **First, try to do no harm.** Human rights and the public good are paramount.
- **Get it right.** Check your facts and your sources, even if deadlines are put at risk.
- **Do not raise false hopes.** Be especially careful when reporting on claims for miracle cures or potential health scares.
- **Beware of vested interests.** Ask yourself who benefits most from this story.
- **Reject personal inducements.** Always make it clear if material is being published as a result of sponsorship.
- **Never disclose the source of information imparted in confidence**
- **Respect the privacy of the sick, the handicapped and their families, at all times.**
- **Be mindful of the consequences of your story.** Remember that individuals who may be sick or handicapped – especially children- have lives to live long after the media have lost interest.
- **Never intrude on private grief.** Respect the feelings of the bereaved, especially when dealing with disasters. Wherever possible avoid close-up photography or television images of victims or their families.
- **If in doubt, leave it out**

Principles to Observe – Royal College of Anaesthetists – February 2003

Raising the Standard: Information to Patients includes the following principles:

- Write honestly, accurately, comprehensively and clearly with no false reassurance about competence or outcomes.
- Base what is written on evidence, providing references to evidence and further information.
- Develop the materials in partnership with patients and patient representatives throughout the process.
- Ensure materials reach patients in good time.
- Present material in such a way that it can easily be translated and put into different formats for different groups of people.
- Be honest about options that may be available in some hospitals and not in others.
- Avoid bossy or 'talking down' statements such as 'this is difficult' or 'you can't understand'.
- Ensure that the level of detail is suited to the audience and that simplification is not at the expense of accuracy. More than one version may be needed to ensure wide readership.
- Check for available guidelines for specific audiences. [e.g. those with poor sight]
- Review and update regularly, by an appropriate group, including feedback from all parties.

European Federation of Pharmaceutical Industry Associations (EFPIA)

Enhancing the Provision of Health Information to Patients in Europe: A Policy Memorandum¹⁵ – June 2004

EFPIA set out a strategy concerning the provision of information on prescription medicines to patients and is based on six principles.:

- Enhanced access to health and medicines information is needed for all patients and citizens in Europe
- Quality medicines information from multiple sources should be promulgated
- Opportunities for Internet access to medicines information should be enhanced
- Regulatory developments should build on current best practice in Europe
- A comprehensive information strategy that will truly benefit patients and citizens in Europe should be developed
- Public Private Partnerships should be one part of a comprehensive strategy

Advice for risk communicators: Weinstein¹⁶ – March 2004

Dr. Weinstein gives the following advice for risk communicators:

- Use the "1 in N" ratio (e.g., 1 in 483) if individuals need to only consider the size of the risk or if comparing a pair of risks. Dr. Weinstein suggests avoiding this format for all other purposes.
- Avoid the odds format (e.g., 5 to 1 odds) because it can be very confusing.
- Keep the denominator constant across probabilities (do not use, "2 in 100" for risk A and "6 in 10,000 for risk B" - "200 in 10,000" allows for easier comparison than "2 in 100")
- Avoid using percentages if they are less than one (e.g., 0.15 percent) or if they are decimals (e.g., 24.15 percent)
- Avoid presenting risks in overlapping categories (do not use "1 in 43 chance of fracture" and "1 in 483 chance of hip fractures")

¹⁵ Available at www.efpia.org/4_pos/informedpatient/policymemo0604.pdf

¹⁶ Weinstein, ND, *Computer-Based Risk Communication: Correcting Colorectal Cancer Misperceptions*, *Journal of Health Communications* (Mar 2004)

Clear guidance on how to present risk information is considered to be critical, though there are no strong candidates for a reliable method for presenting such information. A 'risk ladder' model (see box below) was mentioned as having been used in the UK, but it is now felt to be inadequate, especially in communicating risk over time. This was known to be a topic under research at present.

Example of 'Risk Ladder' – from Bandolier 28 (June 1996 – www.jr2.ox.ac.uk/bandolier)

Risk level	1 in: Range (per year)	Risk of death from disease	Violent/accidental death/other
1	1–9		
2	10–99	Any cause of death	
3	100–999	Cancer, stroke, coronary	
4	1,000–9,999	Peptic ulcer	
5	10,000–99,999	Arthritis, asthma, diabetes, cirrhosis	Road accident, burns, falls, suicide
6	100,000–999,999	Pregnancy, STD	Homicide, railways, aircraft
7	1,000,000–9,999,999	Tetanus, measles, whooping cough	Falling objects
8	10,000,000–99,999,999	Acute rheumatic fever. Acquiring "new" form of CJD	Lightning, animal/ plant venom, Winning the lottery

Data taken from mortality statistics in England & Wales in 1981

Appendix 2 – Good Practice examples

There are many examples of good practice, though they may not be widely publicised. Some of the examples that have been raised at conferences as part of the TIP projects are detailed below, categorised by the area of patient communication affected:

Doctor-Patient Communication

— “Doctor-Patient Partnership”

The DPP is a UK charity (www.dpp.org.uk), which aims to: encourage better communication between patients and healthcare professionals, promote the responsible use of NHS services, and offer practical advice on self-medication. They provide a repository of patient leaflets and promotional items and work closely with other bodies such as patient groups.

One of the recent activities was ‘Ask about Medicines’ week in October 2003 in conjunction with PECMI (Promoting Excellence in Consumer Medicine Information) and the Medicines Partnership to promote awareness and the safe use of medicines.

— Work on “concordance” and shared decision-making

The concept of concordance (as opposed to compliance where ways are sought to persuade people to take their medicines) focuses on the need to adopt a different model of the patient-prescriber relationship and shared decision-making. This has been strongly promoted by the Royal Pharmaceutical Society of Great Britain (RPSGB), including a report ‘From compliance to concordance’ published in 1997 and a report by the All-Party Pharmacy Group to Health Ministers in July 2000.

— Clinical Evidence journal (www.clinicalevidence.com)

This journal was cited as giving physicians options (based on firm evidence rather than hearsay) as opposed to prescriptive behaviour. This supports change in practice without imposing a straitjacket, allowing clinicians to respond to the particular circumstances.

It was felt that there is a need to do the same for patients – viz. provide information about treatment options (couched in suitable language) and let the patients and their clinicians decide what is most suitable in the circumstances.

An example of simple adaptation to the patient perspective

Prof. Leslie Findley, a specialist in Parkinson’s Disease (PD), considered the apparent paradox whereby doctors thought that they spent a lot of time explaining matters to patients, but patients thought that doctors told them very little. He decided to alter the process by which he communicated with patients.

Rather than simply telling patients what their diagnosis was, he started by asking the patients ‘what do you think is the matter with you?’ – this allowed him to assess what they already knew and to gauge what level of detail they might need when he explained the diagnosis.

Having explained that the diagnosis was PD, he then asked ‘What do you know about Parkinson’s Disease?’. This allowed the patient to direct the following conversation and set the appropriate level of discussion.

Being aware of the evidence that patients rarely recall much of what they are told in a consultation. Prof. Findley always arranged a short first interview of 20 minutes, where the basic facts could be discussed, followed by a longer one-hour session where matters could be explored more fully after the patient had had an opportunity to absorb the diagnosis and the information from the first session, and have determined what were the critical questions for them.

Involving Patients in managing their own care

— The “Expert Patient” experience in the UK

The UK Department of Health set up an ‘Expert Patients Task Force’ in 1999, under the leadership of the Chief Medical Officer, Professor Liam Donaldson, to bring together the work of patient and clinical organisations in developing self-management initiatives for those with chronic conditions. Detail is available at www.doh.gov.uk/cmo/ep-report.pdf.

— Dutch “Personal Budget Management” initiatives for chronic disease patients.

In the Netherlands, chronically ill patients are provided with a ‘personal budget’ so that they can choose how they wish to be supported from additional treatments (possibly alternative medicines) to modifications to cars and homes to better support the quality of life. This allows supportive treatment to be tailored by the patient rather than prescribed by the healthcare system.

Developing materials for and with patients

— BMJ Best Treatments

This initiative run by British Medical Journal uses material from its sister publication, Clinical Evidence, to repackage the information into a form designed for members of the public (see Nash B, Hicks C, Dillner L. Connecting doctors, patients, and the evidence. *BMJ* 29 March 2003, 326:674.). This allows patients to have access to the same evidence-based information as is available to clinicians.

This was adopted in April 2004 by NHS Direct Online to make this information more widely available to patients in the UK.

Raising the Standard: Information to Patients

This is a publication by the UK Royal College of Anaesthetists and the Association of Anaesthetists of Great Britain and Ireland, covering the background and evidence for improving the provision of information to patients, details of how they ran a programme of consultation to review current materials, identify patient needs, and develop new exemplars of materials.

It was an extensive project requiring considerable commitment by the College and the Academy and the project team itself. It is an excellent document, published in February 2003, which is currently available at www.rcoa.ac.uk

Unfortunately, it has been poorly disseminated and has few cross-references on the web. Indeed, the Royal College’s own ‘Patient Information’ section continues to show patient information materials that clearly pre-date the report, which are distant and difficult to read – the new materials are also available, but secondary to the older materials. A CD-ROM with templates of the materials is available with the printed copy, but cannot be downloaded.

It is hard to believe that, after such an effort, little has been done either by the RCOA or the UK Department of Health to build on this. The DoH does have its own ‘Patient Information Toolkit’, but this is little more than an exercise in good graphic design and managing the NHS branding (indeed it is supported by the NHS Branding Unit). It is available at: www.nhsidentity.nhs.uk/patientinformationtoolkit

This is unfortunately a classic example of what often happens: a local initiative creates local good practice, but is not replicated further.

Involving Patients in improving Healthcare

— Cochrane Consumers and Communication Review Group

This international collaboration looks at issues concerning communications with patients and their involvement in the provision and management of healthcare, looking at promoting evidence about interventions in this area.

The Consensus conference discussed the option of a similar initiative to create a central repository for patient information with public access. It was felt that this would be extremely beneficial, both to patients who can access the system, and to healthcare professionals in order to access effective communication tools and techniques.

— European Union Health Policy Forum

The EU Health Policy Forum is an information and consultation mechanism involving stakeholders in the health field, which aims to ensure that the European Commission's health strategy is transparent and responds to the public concerns. It is composed of three complementary elements: a Health Policy Forum, an Open Forum and a Virtual Forum. This was felt to be a key initiative to help build the Informed Patient vision.

— Patients Forum

The Patients Forum is a network of organisations in the UK concerned with the healthcare interests of patients and their families and carers. Its aim is to provide a forum for national and regional organisations representing the interests of people who use health services to share experiences, information and ideas, to strengthen their work and to participate in informing and influencing decision-makers. Its membership consists mainly of patient groups though with mainly of the medical professional bodies as associate members. It has commissioned a number of studies concerning patient involvement in the provision of healthcare services.

Patient-provided health information

Dr. Richard Fitton, Hadfield GP UK, has patients take their own blood pressure at home and record it against their electronic health record (EHR).

This not only increases patient involvement in their care and condition, but also gives a more realistic picture of their condition within their normal environment, despite the possibility of greater error in the actual process of recording.

This can greatly improve the range of data available for analysis as well as reducing the cost of data collection (to both the healthcare system and the patient) by reducing clinic attendances. In the future, systems could provide the GP with early warning of poor conformance to drug regimes or possible worsening of conditions.

Encouraging/Publicising Good Practice

— Awards for the best patient information leaflets

The National Council on Patient Information, a US charity, has awards to individuals on work done to support medical communication about medications.

The Plain English Campaign works across many areas, including healthcare, to promote clear public information through its Plain English and Golden Bull awards.

The Focus Awards are a joint initiative between the Department of Health and the British Dental Association, set up to recognise and reward patient-focused innovations within dental practices.

Similar activities at the European level would help identify best practice and promote the publication and sharing of innovative initiatives, including other media such as compact discs, websites, and films.

EU e-Health awards: first instigated in 2003, these have raised the profile of individual efforts as well as promoting similar activities in other countries.

e-Health awards 2004

Information tools and services for citizens: Health on the Net (HON) Foundation for promoting health information quality

Administrative support tools and services: Danish Public Health Portal, which provides information to the citizen as well as including services such as online appointment booking, email consultation with GP, and prescription renewals.

Homecare and telemedicine tools and services: Daibcarnet in France, providing an online logbook for diabetic patient monitoring

There were also 'honourable mentions' for runners-up as well as references to all nominated projects.

Gathering Evidence on Health Information Provision

— The Community Guide (USA)

This initiative is federally sponsored and produces systematic reviews regarding population-based interventions in three general areas: changing risk behaviours; reducing diseases, injuries, and impairments; and addressing environmental and ecosystem challenges. In a number of cases, these include mass media strategies. They publish the 'Guide to Community Preventive Services' at www.thecommunityguide.org.

Learning from Patients' experiences

— Complaint procedures as mechanism for improvement

At the Dublin conference, Alastair Graham of the Irish Eastern Region spoke about their new complaints procedure, part of their People Matter programme, as a mechanism for improving services and becoming more patient-focused, including better shared decision-making.

The UK NHS Magazine of October 2001¹⁷ notes some of the difficulties of simply recording the satisfaction rating given by patients. As an example: a cardiac patient who collapsed at a GP surgery, was given inappropriate food in the cardiac ward (sausage roll and chips!), general lack of information, and early discharge because of lack of beds, noted in a 'discovery interview' that 'Overall, I must say that everything was okay. I have no complaints with anything.'

Patients make allowances for inadequacies of their care, and may not express concerns through simply not understanding that there might be alternatives. The result will be that patient satisfaction surveys can give an overly optimistic view of how effectively a service is delivered to patients, who would probably find such service completely unacceptable in any commercial relationship (e.g. in a restaurant).

At the Basildon & Thurrock University Hospitals NHS Trust (UK), the Chief Executive required an action plan for corrective action with the draft letter in response to a patient complaint¹⁸. This action plan was then followed up and included in the Trust's 'risk register'. This not only ensured that actions were planned at an early stage, but that there was a clear lead from the top of the organisation.

— Getting feedback from patients

In 1999–2000, the London Ambulance Trust developed a system of feedback from patients called 'How did we treat you?', which involved leaflets for patients to feedback their reviews to the trust¹⁹. As a result, the trust received more than 250 enquiries a month, which have led to many improvements to the care afforded to patients.

More generally, the Picker Institute runs a series of surveys for NHS Trusts to get feedback from the public on the services provided (see www.nhssurveys.org). However, these are more geared to comparative performance assessment.

¹⁷ Available at www.nhs.uk/nhsmagazine

¹⁸ Reported in *Achieving Improvements through Clinical Governance published by the UK National Audit Office (2003)*

¹⁹ Reported in *Achieving Improvements through Clinical Governance published by the UK National Audit Office (2003)*

Health Promotion in the Workplace

— Work-related health issues

The ENWHP publications related to Models of Good Practice detail a number of activities at exemplar companies which have addressed possible risks at work, leading to improved morale and reduced illness and absenteeism.

— Information Campaigns at work

From the same publication, GIE Ellis is given as example where female employees were given information (a film and supporting leaflets) on breast cancer. Further campaigns on heart disease and back problems were planned.

Bridgend County Borough Council (UK) also ran a campaign relating to back-related illnesses, including awareness and proper training, leading to significant reductions in absence from work and staff turnover.

— Pro-active management for elective surgery

Professor Detmer had personal experience of working closely with a large corporation in managing elective hip replacement. Employees had often experienced anxiety in taking absence from work in order to have and recover from elective surgery. Some employees would return to work too early and suffer poor outcomes as a result.

By involving the employer in the planning of the absence, patient anxiety could be reduced, disruption to the workplace reduced, as well as allowing proper planning of a managed return to work which can suit both patient and employer.

Other work has shown that maintaining close links with colleagues at work during prolonged absence can improve patient recovery through reduction in anxiety and maintaining social connections with workmates.

Public Health Communication

— BBC 'NHS Day' events

There have been two of these events so far (2003 and 2004) which may have raised public awareness of the healthcare system and how it works, though the main objective was a public debate on healthcare priorities. It should serve to make the public more aware of how the system works. We are not aware of any published material on the effectiveness of these events.

— Use of 'soap operas' as communication channels for health issues

There are a number of well-recorded successes in Africa of the use of 'soap operas' (usually radio) to promote awareness of key health issues (e.g. AIDS and proper use of condoms). Lessons learned have been to make the programmes meaningful and interesting to the target population before introducing health messages which must only be incidental to the main drama.

The situation in Europe will be different, mainly because of commercial interests, but also because of the much wider competition between channels and existing 'soap operas' as well as many different social issues which will be addressed. There are many 'hospital dramas' already available, which can easily carry public health messages, but these are often geared to 'accident & emergency' scenarios rather than long-term chronic health conditions.

Appendix 3 – European Centres in Patient Information

Organisation	Centre Lead	Area of study/focus
Cambridge University Health, UK	Prof. Don Detmer, Peter Singleton	'The Informed Patient' reports – policy options to improve patient information provision
Department of Primary Care, University of Swansea, UK	Dr. Glyn Elwyn	RADAR (research about decisions and risk) group
University of Leeds, UK	Prof. Theo Raynor	Medicines information: Package Insert Leaflets (PILs), concordance
University of Keele, UK	Prof. Blenkinsopp	Medicines Management
Picker Institute, Europe, Oxford, UK	Prof. Angela Coulter	Patient surveys across Europe
Institut de Sciences de la Santé, Paris, France		Europe Blanche XXV conference: Sharing Health Care Decisions. Informing and Empowering Patients
Trinity College Dublin, Ireland	Prof. Jane Grimson	eHealth tools to help patients
British Medical Journal, UK	Dr. Luisa Dillner	'Best Treatments' information for patients derived from clinical evidence
Netherlands Institute for Care and Welfare, Utrecht, Netherlands	Pim de Graaf	Best practice on electronic patient information
Escuela Superior de Relaciones Publicas, Universidad Industrial, Barcelona, Spain	Dr. Antoni Noguero	Public Communications in Healthcare
University of Florence, Italy	Dr. Pierangelo Gepetti	'Il Paziente Informato' conference
Viharlaakso Health Center, Espoo, Finland	Dr. Osmo Saarema	The impact of information technologies on health care – the patient and the internet
University of Wales, Cardiff, UK	Dr. Tony Bayer	InfoPark project, developing information on Parkinson's Disease for patients, carers, and non-specialist professionals

CUH is keen to hear of other centres or sources of materials – please e-mail to:
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