pif **Patient Information Forum**
For Professionals Working in Consumer Health Information

Date: June 2014

Creating health information that really works

Reporting on the engagement process March 2014- May 2014

Contents

Background

With funding from the Department of Health, PiF and its members are creating the UK's first practical, producer-led guidance and best practice on creating great health information resources.

We all want to create the best information we can; information that makes a real difference to the people who use it. There is a growing need to understand 'what good looks like' and how to produce it consistently. One of the best ways to do that is to learn from what others are doing; see what works and what doesn't and be able to see clearly what 'good' looks like. To do that we need the right tools.

This project aims to produce practical materials, tools and guidance that will help any individual or organisation to achieve consistently high standards. And just to be clear, these tools are about the end product, not the process, to ensure we have engaging, usable, effective resources for the public.

The issues and ideas identified at two 'Open Space' events in March 2014 were developed further in a follow-up event on 14 May. 75 people attended the March events and 22 people attended the May event. This report summarises the work that emerged from this process and will inform the project steering group in taking the work forward in order to start offering guidance/resources from autumn 2014.

As the work unfolds there will be further chances to input and 'user test' it and to expand the numbers contributing through an online survey. More details about the project can be found at www.pifonline.org.uk

What the March events prioritised for the proposed resource

The full lists of top priorities are given in the Annex along with the amalgamated priorities from both events as well as a comparison table. Analysis of this material clarified that there are **four critical areas** for the resource to focus on:

Critical area	Including
Making sure information works for users	- Being clear about your audience - Involvement of users throughout process including leading, developing, presenting and robustly testing information products - Integrating information into people's healthcare and 'patient education'; producing information that enables and empowers - Enabling access when people want/need it - Avoiding duplication but ensuring information stands out

Formats for information products	• Digital and audio/visual formats • Personalising products for groups and individuals – audience focus
Readability & engagement	• Accuracy and use of evidence alongside stories and personal information • How to present risks/benefits • Attractiveness with non-patronising approach • Plain English • Involvement of users • Easy navigation
Evaluation and measuring impact	• What do we know works? • How information can make a difference • Making sure information is used • Measuring impact for the user: what is the value/benefit to them?

Developing the guidance resource

This section gives an overview of the issues for the proposed resource: overarching principles and cross cutting core components of developing good health information. It then goes on to report the material generated at the May event addressing the four critical areas identified.

Overarching principles

It was clear from the discussion in March and in May that a number of issues appeared consistently across all topics and arguably form a set of overarching principles for creating consistently good health information.

These principles include (this list is not exhaustive):

1. **Have a clear purpose for the information and share this with all involved**
2. **Talk to and involve potential users from the start and throughout: 'follow the information user at all stages'**
3. **Less is more…keep information simple and clear**
4. **Personalise information wherever possible; one size does not fit all**
5. **Make sure information works in the 'real world' for all involved or affected**
6. **Check what's already available and think outside your organisation: link to and share good work, knowledge and expertise across professional boundaries and across the professional/patient/public boundary**
7. **Information shouldn't stand alone. It needs support, so it can become knowledge, education and empowerment**

Core components for developing good health information

What also became clear through the discussions is the interlinked nature of core components for producing good information. There are many cross cutting themes and you can't really say: 'start here'. Starting points depend on the context and triggers for the work and developing the information will involve an iterative process taking in all aspects of information

production, delivery and evaluation. This may present some challenges for the development of guidance. For example, user involvement, testing, planning and evaluation are important aspects of every stage of development.

Addressing the 4 critical areas

At the 14 May follow up event, participants were asked to join one of four groups looking at each of the areas identified in the Open Space events. Participants could change group part way through the day if they wished to.

Groups addressed each area by asking four questions:

1   Which of the issues/ideas raised in the events about your critical area would it be MOST USEFUL to include in the proposed guidance?
2   WHAT ELSE, if anything would it be useful to include on this critical area?
3   What EXAMPLES/LINKS/PROJECTS/SOURCES/PEOPLE can you offer to help develop this critical area? Be as specific as you can.
4   What kind of FORMAT or PRESENTATION do you think would be most helpful for engaging guidance users, and providing practical support in relation to this critical area?

Below is a summary of all of the issues raised and any guidance that was suggested.

A   Making sure information works for users

Keep it patient focused

- Be clear about the audience, what they need and why. "Follow the customer."
- Consider a patient's information journey. They will have different needs at different stages. Identify a user's pathway, where and when they are on the journey, and the key points where they will have information needs. But don't offer rigid provision; offer it as and when it's needed.
- Use pathway mapping of information needs (for example – GOSH, Info prescriptions for 50+, Cancer types).
- Don't focus on the clinical or the official point of view, and don't focus on protecting the institution or the health professional. Diagnosis and medical needs are often met by information, but not Quality of Life issues.
- Make it about patients' needs and be holistic.
- Consider FAQs. It's about patient education not information.
- Ask if the information is needed and what you want users to do with it.
- Don't over simplify. Give enough evidence-based information to make a decision.
- Don't work in isolation.
- Acknowledge that sometimes a leaflet isn't best; a conversation may be better.

Patient co-production.

- Involve users from the start: scoping, testing and evaluation. Producers must alter their mind set from 'to' or 'for' to 'with'.
- Value peoples' stories, capture their experiences, and make it real.
- Understand the community. Community development techniques can be valuable. But acknowledge that there are practical caveats to this (time, expense, lack of drivers).
- Engage with patients and real people to plan. Be creative, and get people seeing the value of changes, so that they get involved.
- Don't forget those with low-literacy levels or those who are socially excluded. Probation clients can be used as proxies (as done by Prostate Cancer UK). Also work with faith groups.

> ⇒ PiF could give clear guidance on the steps to engage with patients and users, and how to recruit beyond the usual suspects.

Make it high quality

- Consider who is best placed to produce the information, or has it already been done? Are you the best person? Should you avoid duplication? Or is duplication not always a bad thing?
- Avoid waste. Can organisations cross link, work together or save money. For example, there may be opportunities to share tools, IT resources, mail houses, content. For this to be a success, branding and funding issues may need resolving.
- Use generic information if it's available. Reconcile national (generic) information with local information. Add flavour to what's already out there. Use other available guidance.
- Some users want independent information from several different sources. Acknowledge that this second opinion is OK. Signposting is important.
- Define what core skills are needed to produce content. Clinicians may have the skills to appraise and identify content, but info producers may be better placed to produce it. Give advice on how to manage agreement between the two parties.
- Consider who has what skills. Share expertise (for example, clinicians, and patients). Consider training, such as CASP.
- Work with HCPs as producers, reviewers and distributers/'gate-keepers' right from the start. For example, the British Heart Foundation has run a project recently where they have engaged GPs from the start.
- Look for external reviewers. For example, help may be available from CRUK, Macmillan Cancer Support, Mind (non-clinical reviewers), and NAM (aidsmap.com).
- Managing health experts as part of the multi-disciplinary team of producers/reviewers can be difficult. Most will review pro bono but this can be tricky. Give them a brief, and keep them focused with clear deadlines.

> ⇒ Members would like PiF to produce a step-by-step guide on how to produce information and what not to do. Include examples/case studies to flesh out the

guidance. Signpost to The Information Standard and other such resources. Acknowledge that it's difficult to get it right.

⇒ PiF could also pull together a central repository of guidance on writing, testing, funding, disseminating, scoping, and the digital world.

⇒ PiF could give clear advice on involving health experts. How to engage them, pay them, manage them, brief them. Include example contracts or letters of agreement.

⇒ PiF could produce a guide to getting funding: how to get money for information development (such as the Big Lottery Fund, NHS funding routes) and example of who has done what. Share experiences of whether to charge or not. Acknowledge that without investment a lot of this is impossible.

Make sure it reaches users

- Consider how the information will be disseminated. What is available locally already. Do you need to tailor the information accordingly so that it will actually be used?
- What impact will 'gate-keepers' have (such as local practitioners who you hope will disseminate)? If it doesn't work for the disseminators, it won't be used. But don't sell yourself short. Is this tension a problem? How is this resolved?

Don't let the product fall into the abyss.

- Have a launch strategy. Make your information stand out from crowd.
- Is a top-down approach needed (for example, NHS England, NHS Choices, regional programmes)?
- Don't work in isolation. Involve stakeholders at the 'top' (e.g. NHS Choices) and 'bottom' (patients, nurses, those who will pass info on).
- Commercial promotion companies may offer advice or support (though this would probably need funding).
- Integrate information into healthcare delivery: engage with clinicians and other health staff; use other resources; consider limitations of the NHS. Standardise some information.
- Promote good examples to staff. Provide an easy-to-use framework for staff to use. Or consider in-house training from experts to embed best practice. Have information champions within teams.
- Consider information providers - can clinical libraries provide an information service to patients? Do we know about, and maximise the benefit of, information centres? And the Information prescription service?

⇒ PiF could provide a library or sharing forum for case studies; examples of information, research, challenges and impacts; good practice and examples of learning; working examples of when people have resolved issues; documents that others can use; what you need to think about when commissioning information.

⇒ Be a host for a repository of best practice that others can upload to.

B   Formats for information products

Choose the best format

- New technology is *de rigour* but does it warrant the focus it gets, and the priority funding? Don't just jump on the bandwagon. Think carefully about the right resources for your audience. There will be a shift to digital-first sooner than we think. Meanwhile remember the danger of going solely digital and so excluding paper-only audiences.
- Technology can be an enabler as well as a barrier. It is getting cheaper to produce. New formats may not be as difficult or costly as you think, and may be more acceptable and appropriate to some users. Don't be daunted by the prospect of embracing a new way of information provision. Instead, give it a go, even if it's a small step.
- Know your audience. Ask them what they want.
- Information in accessible formats is a legal obligation – you must provide it if asked and publicise that you can provide it
- Remember that not everyone is online; but the numbers who are is increasing, particularly older people.
- Different groups of users may need different formats. But don't make assumptions. For example, not everyone with visual impairment needs braille. Some myth-busting may be necessary.
- Can we afford to take into account everyone's' preferences?
- Use what's out there. Do your research. But also identify where the gaps are so that people don't go elsewhere.

Analyse users' information needs regularly

- Before you start, speak to people/organisations who are already getting it right.
- Print-on-demand can work well, especially with online versions that have been re-designed for print. But hyperlinks can be lost. And there is the cost of printing multiple sheets, or not having decent print facilities. Printing at home or in the NHS, especially in colour, can be problematic.
- Should all information available in print also be available online?
- As we shift to digital, we need to know more about how people respond to different formats (reading online instead of paper). Books and leaflets aren't dead! Offer a choice. Use complementary formats together (e.g. audio visual can support written word, helps with literacy and can give supplementary information).
- Consider problems of HCPs hoarding paper copies, vs. downloading electronic versions and not updating them. Or whether the NHS print facilities are good enough.
- Perhaps online resources can be used to improve HCPs use of information, and even personalise it.
- Going digital needn't be difficult. Doing something is better than nothing. Make it a core activity. It could save money and supplement other information. It can be very valuable having all information available together.

- Make it part of the planning and review process to consider what is changing (including audiences and formats).

> ⇒ PiF could provide a knowledge hub defining which groups need what alternative formats and what best practice is.
> ⇒ PiF could create specific guidance on how to produce information for groups with certain needs.

Core principles still apply to new digital formats

- Core principles of information provision and high-quality information apply to different formats.
- Collect examples of good practice, both in terms of the process and the end result. Also, gather templates for print, online, video, social media, and user-generated information (N.B. with the latter you lose control of the content, and quality can be an issue).
- Involve experts – clinicians, patients, technologists.
- Modifiable templates would be useful for producers, giving questions to answer about any procedural condition or service.
- Investigate GP software packages and what they provide.
- Ensure information is freely available and accessible. Try to mitigate the problems of paying for information, signing in, not finding it online, being bombarded with information, not having the IT skills needed to use the resource.
- Keep it simple.
- Put the information that is important to the patient first.
- For producers that worry about litigation, personal stories can work well.
- Lobby for a central bank of translated material.
- Make sure a Word version exists so that all documents can be enlarged.
- Tag PDFs to make them more accessible.
- Advertise what information and what formats are available.
- Digital resources may have the flexibility to offer more than one route into the information. For example, rather than focusing only on conditions, it could also start at symptoms, or lifestyles.
- All formats must be kept up to date
- Are there resources that haven't been tapped? For example, Parkinson's UK used a patient's son to create a video. You Tube has lots of tutorials.

> ⇒ PiF members want technical guidance. But don't reinvent the wheel – much of this can be achieved by linking to guidelines published elsewhere.
> ⇒ Offer advice or links to tips and hints on things such as formats, platforms, file sizes, iTunes attributions, and blocked attachments. For example, certain formats go across platforms, whereas Flash doesn't.
> ⇒ Basic design standards (such as colour, fonts, size etc)
> ⇒ Glossary of technical terms
> ⇒ How to create an app, podcast or film

> ⇒ Information architecture for websites and how people navigate, search etc
> ⇒ Altering writing styles for digital output such as social media, online, video scripts
> ⇒ Explanation of copyrights, syndication etc
> ⇒ Guidance on using and developing infographics.

C   Readability and engagement

Make it accurate, evidence-based, targeted and engaging

- Consider the purpose, audience, context and accessibility issues.
- What questions are people asking (for example, in forums or with health professionals)?
- Use quotes, tips and stories.
- Include non-clinical information about living with the condition, or other patient experiences.
- Use evidence-based resources, guidelines and literature review. Be transparent if there is no evidence.
- Use multi-disciplinary teams for creation of content and health professionals to check for accuracy.

Presentation, tone and language are crucial

- Make it attractive, short and engaging for its purpose and audience.
- Everything must amplify readability and make key messages more understandable.
- Think about images, packaging, colour, titles, how people choose.
- Allow for varying levels of knowledge and literacy by chunking information into key points that can then be elaborated on.
- Keep it simple, focused and use simple language, short sentences, clear headings, plain language etc.
- Look at guidance on dementia, poor cognition and memory.
- Use every day spoken English rather than strictly grammatically correct English. Avoid jargon.
- Think about the reader's perspective, and their concerns, to guide the structure.
- Tables can be useful but test to see if it's simplifying or confusing.
- Put positive information/benefits/important information first. Put the 'why' before the 'How'.
- Put the 'do' statements first, and the 'don't' towards the end.
- Questions and Answers can be helpful but sometimes need using with caution because of tricky questions.
- Consider readability scores; SMOG; number of ideas per sentence; health literacy (Gill Rowlands); Theo Raynor's Golden Rules).
- Colour, text boxes, side panels, summaries, images, graphics, bullets, 2-levels of headings can all help readability if done well.
- Use web analytics to find out where people go/link to.

Communicating risks and benefits must be done carefully

- Consider numeracy of population.
- Start with patient's point of view.
- Use clear infographics; absolute risk numbers, natural numbers; avoid percentages (but give examples of how else to represent data). Balance with benefits.
- Consider individual prescriptions of risk/benefit. If not possible, make it clear that risks are presented at a population level.
- Warn/signpost potentially scary or sensitive information.

Involvement of users is vital

- Don't just test understanding. Users must be involved in the planning and evaluation.
- If something needs updating, show users the old version and ask them what needs changing.
- Users must be truly representative, not just the highly educated, engaged, keen patients!
- Break down the barriers to involvement. Try to attract different groups. Engage with existing groups and create new ones.
- Explain that involving participants is beneficial to them. They may feel valued and like contributing.
- Be clear what you want to test. Plan thoroughly. Be creative.
- To find users, link with other charities or community groups, social media forums, nurses and HCPs.
- As well as patients, involve intermediaries such as volunteers, HCPs and carers.
- Test in more than one way.
- Remember, testing is very beneficial to the producer too.
- How do we interpret and make use of the information that you get from testing? For example, not acting on everything said, such as putting warnings in red.
- Consider logistics when inviting users to attend sessions, such as payments, biscuits (!), travel.
- Learn from the world of medicine leaflets, which has been user-testing readability for years.

⇒ PiF could give links to, or clear explanation of, data on poor reading, literacy and numeracy and health literacy, so that people understand how important it is to follow guides from such as Plain English and DISCERN.

D   Evaluation and measuring impact

- When considering an evaluation, ask who has done this already? What exists already? Share research methods and results.

- Be clear, before you start a project or any evaluation, what your objectives and purpose are: what you want the resource to achieve. Include users in determining the objectives. Planning is essential.
- Objectives should be measurable and realistic.
- Choose which materials should be evaluated. Think about how people will use it and when.
- It's not just an evaluation of the resource, but also about the impact it has had, or its outcome measures.
- Include appropriate levels of evaluation (quick, medium, exhaustive) and think about when this should be done.
- Be realistic about what can be expected. Narrower outcomes are easier to measure.
- There are three groups you could involve: patients and carers, HCPs, and information developers. The wider the evaluation the bigger the picture. But they must be representative and not biased.
- How do you follow up in the longer term? How do you evaluate information when you don't know who has used it? How do you reach users, especially online?
- How do you reach those who are disempowered? Or those who struggle to understand? It is very difficult to get these groups to engage with evaluation. Can HCPs help?
- Most importantly, how to you include those who have not accessed the information or engaged with the intervention?
- Who is the resource addressing? What do they want? What is going on in their lives? Consider where they are in their journey, their language and culture. And so what would be a successful outcome? Let this define the questions you are going to ask.
- Can you link in with others to help evaluate? Who else in the multi-disciplinary team is giving information?
- How can you make evaluation practical for small organisations? Be honest about limitations. Start small but aim big.
- There are various options/tools, such as: Survey Monkey; asking a nurse to evaluate (ticking boxes) during a consultation; adding a link to a survey; face to face meetings (group or one to one).
- Social media could be a way to broaden evaluation opportunities and feedback. Links to feedback could be a route back to the individual for a fuller evaluation, and building relationships more widely.
- Feedback to users: "You said, so we did…"
- Evaluate as part of updating a resource.

⇒ Could PiF distill *The case for information* into a simple PowerPoint presentation to outline the need to measure benefits? For example, look at measuring cost of product vs. improved patient experience and safety etc.
⇒ PiF could create an evaluation template, or standard evaluation Q's, and examples of methods appropriate to the outcomes being measured.

Working example: St Thomas made a video to explain to children about having an MRI. It reduced the need for children to undergo a general anaesthetic. But they didn't do a real evaluation of the effect on medicines use, staff time, patient risk or patient/carer experience.

Resources highlighted

- Health in my language.com
- Genetic Alliance report about patient pathways (GOSH using the idea)
- Screencastermatic website – voice over for PowerPoint
- Hereford hospital maternity department are working with the local film school to produce information on a normal birth
- Google translate
- Apps for hospital maps (GOSH, Queen Elizabeth Birmingham, Christie?)
- Scottish Information Prescriptions digitally
- http://www.senseaboutscience.org/data/files/resources/136/Ive-got-nothing-to-lose_web.pdf helps weigh up claims and cures about medical treatments
- For those with learning difficulties
  - easyhealth.org.uk
  - widgit.com for symbol software
  - booksbeyondwords.co.uk picture books
- Lupus UK are producing some information for schools online-only
- Macmillan have taken some subscription products and put them online-only but free for all
- Parkinson's UK feel their paper newsletter is still necessary for its older population (but people read old versions)
- Asthma UK is going online-only except for its care plans that are bought by CCGs
- Guidelines for medicine leaflet testing:
  - Sless D & Wiseman R Writing about medicines for people: Usability Guidelines for Consumer Medicine Information (2nd edition). Australian Government Publishing Service, Canberra, 1997. First published in 1994
  - *A guideline on the readability of the label and package leaflet of medicinal products for human use*, revision 1, 12 January 2009 http://ec.europa.eu/health/files/eudralex/vol2/c/2009_01_12_readability_guideline_final_en.pdf

Next steps

This report has been shared with everyone that attended the Open Space events or the follow up event, plus members of the project steering group. Given the amount of information gathered during the engagement process, and the work that it would entail to create guidance and tools in all of the areas raised, it makes sense to now take each of the critical areas individually and explore:

- Which of the issues raised are core principles, which are guidance and which are possible future work

- What further information is needed
- Whether there are specific areas that would benefit from a review of the evidence
- What specific guidance and tools would be most appropriate
- Organisations and individuals that may be able to partner with PiF on specific areas and provide expertise and support
- What format guidance and tools would take

Further discussions will be help with the project steering group and following these work will begin to create the actual guidance. The PiF membership and wider health information community should have an opportunity to engage with the development when it reaches the next stage.

Appendix: top priorities from the March events

17 March event in London - Top topics in rank order – total dots for each (where more than 7)

Rank	Topic	Dots
1	Evaluation and making sure information is used and makes a difference	35
2	Key groups to involve in developing health information – and how	31

2	How can we do robust user testing to ensure information is understood?	31
3	How to ensure accuracy in information and use of plain English	22
4	Beyond the written – guidelines for producing audio and visual information	15
5	From paper to digital… producing information that works for all	14
6	Accessibility – can patients access information in the format that they need?	13
7	Use evidence-based resources in the production process	11
8	Easy to navigate and find what you want	9
8	Uniform information on the hospital discharge of older people	9
9	Design	8
9	Patient-focused information not ticking the box for officialdom	8

Top practical ideas that were specifically prioritised (more than 6 dots)

Rank	Practical idea	Dots
1	Include user testing/feedback to check information is understood	14
2	Engage key groups at start of the process and throughout	13
2	Use information that already exists e.g. Stroke Assoc, Age UK. You don't have to do everything, if someone else is producing it use it!	13
3	Use local community groups/community development techniques for user testing to get beyond 'usual suspects'	12
4	Use evidence-based resources in the production process	9
5	Link with other charities/organisations to share users to test information with a wider audience	8
6	Produce standard questions organisations can use to evaluate their information and ask PIF members to share evaluations to broaden knowledge/expertise of information providers	7
7	Create knowledge hub where information on how to produce information for specific groups is easily available	6

25 March event in Manchester - Top topics in rank order – total dots for each

Rank	Topic	Dots
1	What do we know works? And how do we stop duplication/information 'congestion'?	24

2	How do we integrate numbers/facts with experiential information such as personal stories? (and communicate risks)	19
3	How to involve patients/'real people' in the development/improvement of quality information?	14
4	How do we integrate information into healthcare delivery?	13
5	What makes information readable?	12
6	How do we move beyond printed leaflets and pdf's?	9
7	How to create non-patronising health information for people from lower socio-economic groups?	8
8	Standing out from the crowd - how do we stop our information product falling into the abyss...?	6
9	How do we measure if it 'really works'?	3
10	How do we <u>evaluate</u> the <u>impact</u> of information?	1

Top 10 practical ideas that were specifically prioritised (4 dots or more)

Rank	Practical idea	Dots
1	Offer many ways to engage patients to attract different groups	9
2	Share good examples of what works and to stop duplication	8
3	Less can be more - keep it simple	7
3	Be clear about your audience - who do you need to engage with?	7
4	Use patients 'real people' to tell the story	6
5	Get clinical and exec staff on board with patient education through CQUIN, legal, culture change - learn from paediatrics	5
6	Look at patient education NOT information - e.g. pre-op, 24 hr chemo helpline - encourage patients to own their own life	4
6	Consolidation & evidence synthesis	4
6	Need critical appraisal skills	4
6	Have to see the value/benefit for the user - what is the change for them	4

Overall topics ranking – incorporating both events

Rank	Topic	Total dots

1	Evaluation and making sure information is used, makes a difference, 'really works'; measure/evaluate impact	39
2	From paper to digital... beyond the written - move beyond printed leaflets and pdf's - guidelines for producing audio and visual information that works for all	38
3	How to ensure accuracy in information and use of plain English? What makes information readable?	34
4	Key groups to involve in developing health information – and how	31
4	How can we do robust user testing to ensure information is understood?	31
5	How do we integrate numbers/facts with experiential information such as personal stories? (and communicate risks) Using evidence-based resources in the production process	30
6	What do we know works? And how do we stop duplication/information 'congestion'?	24
7	Accessibility – can patients access information in the format that they need that's easy to navigate and find what you want?	22
7	How do we integrate information into healthcare delivery? E.g. uniform information on the hospital discharge of older people	22
8	How to involve patients/'real people' in the development/improvement of quality information?	14
9	Design	8
9	Patient-focused information not ticking the box for officialdom	8
9	How to create non-patronising health information for people from lower socio-economic groups?	8
10	Standing out from the crowd - how do we stop our information product falling into the abyss...?	6

Overall top ideas list – incorporating both events

Rank	Practical idea	Total dots
1	**User testing** Include user testing/feedback to check information is understood Use local community groups/community development techniques for user testing to get beyond 'usual suspects' Link with other charities/organisations to share users to test information with a wider audience	34
2	**Focus on audience** Be clear about your audience - who do you need to engage? Use patients 'real people' to tell the story Have to see the value/benefit for the user - what is the change for them Create a knowledge hub where information on how to produce information for specific groups is easily available	23
3	**Engagement** Engage key groups at start of the process and throughout Offer many ways to engage patients to attract different groups	22
4	**Avoid duplication** Use information that already exists e.g. Stroke Assoc, Age UK. You don't have to do everything, if someone else is producing it use it! Share good examples of what works and to stop duplication	21
5	**Using evidence** Use evidence-based resources in the production process Consolidation & evidence synthesis Need critical appraisal skills	17
6	**Focus on patient education** Look at patient education NOT information - e.g. pre-op, 24 hr chemo helpline - encourage patients to own their own life Get clinical and exec staff on board with patient education through CQUIN, legal, culture change - learn from paediatrics	9
7	**Help with evaluation** Produce standard questions organisations can use to evaluate their information PIF members to share evaluations to broaden knowledge/expertise of information providers	7
7	**Less can be more** - keep it simple	7

Comparing top 5 topics & top 5 ideas from each event

1   Topics

Rank	London	Manchester
1	Evaluation and making sure information is used and makes a difference	What do we know works? And how do we stop duplication/information 'congestion'?
2	Key groups to involve in developing health information – and how	How do we integrate numbers/facts with experiential information such as personal stories? (and communicate risks)
3	How can we do robust user testing to ensure information is understood?	How to involve patients/'real people' in the development/improvement of quality information?
4	How to ensure accuracy in information and use of plain English	How do we integrate information into healthcare delivery?
5	Beyond the written – guidelines for producing audio and visual information	What makes information readable?

2   Top ideas

Rank	London	Manchester
1	Include user testing/feedback to check information is understood	Offer many ways to engage patients to attract different groups
2	Engage key groups at start of the process and throughout	Share good examples of what works and to stop duplication
3	Use information that already exists e.g. Stroke Assoc, Age UK. You don't have to do everything, if someone else is producing it use it!	Less can be more - keep it simple
4	Use local community groups/community development techniques for user testing to get beyond 'usual suspects'	Be clear about your audience - who do you need to engage with?
5	Use evidence-based resources in the production process	Use patients, 'real people', to tell the story