



# Patient Information Forum

*For everyone involved in health information and support*

[www.pifonline.org.uk](http://www.pifonline.org.uk)

## Report of Executive Circle meeting

**Thursday 20 September 2018; 1.00-4.30pm**

**Kindly hosted by MHP Communications, 6 Agar Street, London**

### **Communicating Complex Information on Personalised Therapies**

#### **Sue Farrington – Chair, Patient Information Forum**

Sue welcomed attendees and explained how PIF is passionate about high-quality information and outlined PIF's strategic aims. Sue highlighted the information challenges posed by personalised medicines but pointed out people do not always get access to high-quality information where it exists, because of a lack of signposting. Sue recommended the 7 step Perfect Patient Information Journey process, (developed by PIF with the support of AbbVie) to ensure people's information needs are met throughout the patient pathway in long term conditions.

#### **Prof Alf Collins – National Clinical Advisor for the Personalisation and Choice Group, NHS England**

Alf looked at the topic from the perspective of the NHS workforce – what do we want healthcare professionals to know and confidently do, he asked?

Alf explained that people still like to work in tribes. All tribes develop a common language. 'Clinicians are a peculiar tribe, and speak a language I don't always understand. People increasingly talk in code as healthcare becomes more complex'.

This is a challenge when communicating with patients who do not speak the language.

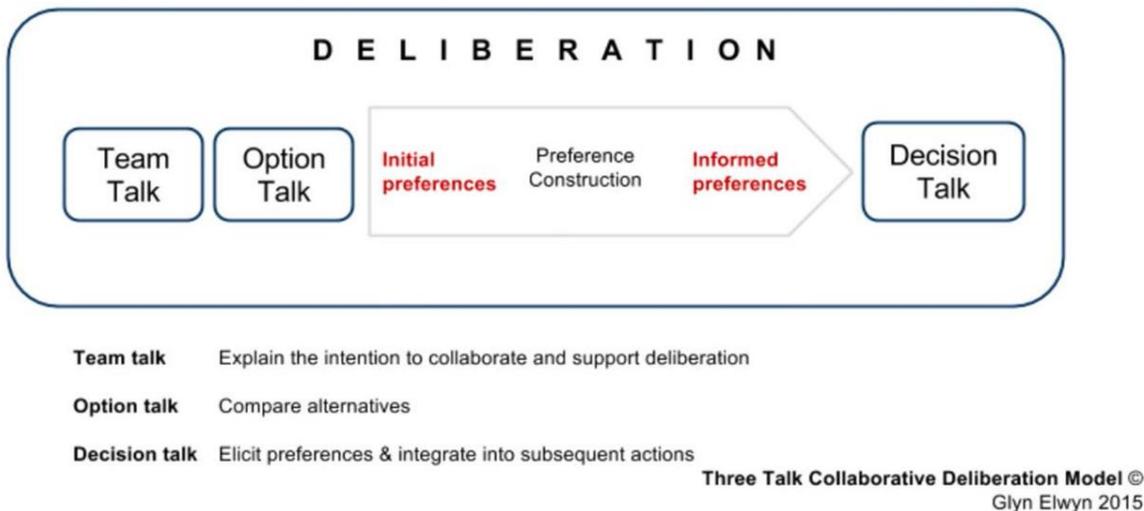
Alf referred to the common-sense model of self-regulation, Leventhal H 1997, and its relevance to patient information and communication.

Diagnosis is a threat to identity and a person's potential future, he said. People make sense of diagnosis according to socio, cultural and economic experience and signals from their body.

As a result, people respond differently when faced with a diagnosis or a complex decision related to it. 40-45% of the population when faced with threatening information, respond with anxiety and fear and use avoidance as a maladaptive response.

“It is really important to consider this when delivering information to people, said Alf. “The wrong health information can trigger maladaptive behaviour in a population. For example, what people know or hear about back pain impacts on their outcome.”

Alf recommended the 3-talk model as a means of developing motivational interview skill.



Skills around communicating risk need to improve, he said “We are rubbish at communicating and understanding risk. It’s a laden statement, but I have the evidence,” said Alf.

Thankfully new e-Learning tools on risk communication for GPs and specialists have been developed by the Winton Centre. These are free to use. <https://wintoncentre.maths.cam.ac.uk/news/winton-centre-launches-elearning-courses>

Always use absolute not relative risk, said Alf, and he cautioned on the use of the word risk. “Risk is perceived as a threat. People can switch off and stop listening. Benefit, harm, uncertainty are what we are trying to express, and chance or likelihood are better terms than risk.”

He also said it was important to discuss the consequences and burdens of treatment alongside benefits and harms when considering a treatment option.

“We tend to think of every intervention in terms of benefits/harms. We don’t think about the other stuff people have to do to take the drug. The monthly blood monitoring, some distance away with an awful car park and a three hour wait. This is treatment burden and it needs to be factored in to shared decision making.”

Alf stressed the importance of health literacy. We need to remember that there is a significant number of people who can’t use a BMI chart or read a drug label.

“It’s not their fault. We are not good at making information understandable.’ Alf said it was better to patronise, white university educated people rather than broaden inequality with complicated information, which is what is happening at the moment.

The only way we can support shared decision-making is to have high-quality health literate information, he said.

Returning to the question what does the workforce need to know? Alf summarised “Remember Leventhal. Use common sense. You will scare people if you don’t use neutral language with folk meaning. It is how people make sense of the world.”

### **Top tips**

1. Start where people are. Helpful optimistic information. Use neutral language. Don’t scare so they switch off and stop listening.
2. Chunk and check. Give information in short chunks and check understanding
3. Teach back – It is about how good you are at explaining information as a healthcare professional. ‘I want to check how well I have explained. Can you tell me what you have learnt? What will you do now?’

See Health Education England’s Health Literacy Toolkit:

<https://www.hee.nhs.uk/our-work/health-literacy>

### **Tom Bishop - Senior Patient Services & Information Manager, Anthony Nolan**

People facing stem cell transplant are faced with a barrage of complex information and they have a huge number of questions. Anthony Nolan have used this experience to prepare for questions on a new wave of personalised cancer therapies, including CAR-T for childhood leukaemia which hit the headlines in early September: <https://www.bbc.co.uk/news/health-45407514>

Given their expertise in stem cell transplant, Anthony Nolan, anticipated a spike in queries to its website and advice line when CAR-T therapy was approved for use in September.

The treatment manipulates a patient’s T-cells which are then returned to the body to fight leukaemia. It is a highly personalised therapy and costs £280K per patient.

“As soon as this story broke we knew this would offer really “personalised care”, said Tom. The charity had already written a research blog, so highlighted it again on its website and shared it on its Facebook page.

The blog answered key questions including: What is this therapy? Will it be relevant to me? Replies to queries that came via Facebook were honest in explaining whether the therapy was relevant to a person’s type of cancer or not.

Tom shared top tips for communicating complex information drawn from the Anthony Nolan’s many years of experience in providing information.

1. Be concise – get the essentials across, starting with the most important essential information and ending with the last. Give yourself one side of A4.

2. Know your audience – don't assume people know nothing.
3. Link everything back to an explanatory resource.
4. Answer key questions and address them directly:
  - What is it?
  - What is it for?
  - Is it suitable for everyone?

The result should be something similar in length to an abstract of a research paper, but without the medical jargon. It is important to use everyday language and memorable phrases, for example, Anthony Nolan's information described CAR-T 'as a living therapy using your own cells'.

Analogy can be useful but should be used sparingly, Tom cautioned. It is also important to be sensitive when it is very hard to predict outcome, use broad figures only. In stem cell transplant, for example graft v host disease will affect 8 in 10, but the Anthony Nolan refer people back to their care team for more personalised information.

It is also vital to manage expectations. Stem cell transplant is only successful for 50% of people over 5 years, so again it is important to refer people back to their team for a detailed discussion.

Anthony Nolan has used a variety of formats to communicate complexity. One of the most popular resources is a fold-out leaflet which gives a visual graphic description of the steps involved in a stem cell transplant from donation to after care. It shows what will happen before, during and after a transplant. This is also offered as an animation on the website:

[https://www.anthonynolan.org/sites/default/files/1346OP\\_Essential%20FactsforTransplantPatients\\_2018\\_WEB.pdf](https://www.anthonynolan.org/sites/default/files/1346OP_Essential%20FactsforTransplantPatients_2018_WEB.pdf)

"It's useful to remember that providing information is not a single event" said Tom, explaining people will make a number of calls to the helpline or visits to the website between appointments and treatment. "It's important to consider what they want to know today" he said. Looking at questions coming to your helpline can also help identify information gaps.

Tom's top tip for communicating complexity was to "keep it simple".

**Information and communication Dr Lynn Furber - International Fellow with the England Centre for Practice Development, Associate Professor, School of Nursing and Midwifery, De Montfort University.**

"Information isn't necessarily communication, so check understanding" said Dr Furber. "When people are faced with a cancer diagnosis they are often unable to process information, so it is important to give basic information and then build on it."

Questions to be considered include:

1. How do we know patients want information? – some patients say they don't want to know anything, so they can remain hopeful.
2. How do you know what patients don't know? This can be really basic, including can I bring someone with me? Can I ask questions? What's a Registrar?
3. Be aware patients will do with information what they will. We produced a booklet to help patients prepare - not everyone used it as we thought, and some people felt they had too much information.
4. How to you know the patient understands what has been said? Remember patients don't want to appear stupid.
5. Disclosure does not mean understanding. If you tell someone they have a tumour they won't know its cancer unless you tell them.

Lynn and her team were able to transform consultations by using a pre-consultation questionnaire which sought out people's preferences and information needs.

Finally, it is important to ask how people feel about cancer and recognise the emotional impact. Lynn reminded people to use the nurse's mnemonic.

**N**ame the emotion

**U**nderstand the emotion

**R**espect the patient

**S**upport the patient

**E**xplore issues

**S**ensitivity

## **Discussion and future action**

Attendees were given 30 minutes to explore, in small groups, their challenges and solutions in communicating complex information.

## **Main discussion points**

1. Targeted therapies e.g. crowd funding for treatments – staying on top of changing treatment landscape and communicating quickly.
2. Interventions are changing – not just drugs anymore – how to explain new treatment services.
3. Challenge medical/regulatory processes to simplify and find the right language to really explain information.

4. Keeping the 'red thread' to ensure communications received across the patient journey on a treatment pathway are complementary/don't break the experience.
5. Barriers to accessible information: assumptions about levels of information needed.
6. Reaching harder to reach groups – Educated middle classes usually do well.
7. How to put patients on a graduated information pathway.
8. How do you reflect how much you know are taking in as a patient?
9. Lack of honesty in consultations. Need to frame risk and numeracy. Stats don't make a difference as the risk is about you not the number. What is relevant to the patient at that point? Being in the 1% of people that get a disease could make a person very annoyed and question why me?

## **Practical recommendations**

1. Format – infographics reflecting the questions asked about why treatment is, or is not, for me.
2. Be clear on what patients want /need to know
3. Regulatory bodies need to improve training/education
4. User testing of material
5. Education of healthcare professionals and other information provider about the literacy challenges people face.
6. Provide questions for patients to ask in second consultation – most valuable. Here are some basic facts and here are questions to ask and now is a good time to start thinking about these. Prompt patients to ask and prepare physicians to expect it.
7. NHS information hub run by information professionals to direct HCPS to high-quality specialist resources. Information Standard and kitemarking.
8. Information is a continuum and not just at one point. Must take long term view. Terminology changes over time. Needs to be a graduated pathway. Personalised.
9. Information should be about the patient's agenda.
10. Make the process smooth across the process and channel used – intake points are multiple – friends, clinicians, etc
11. Understand and reflect back.
12. Get basics in place and build on them.

13. Keep it simple but personal.