



'Patient Voice Initiative' Meeting Next Hotel, 72 Queen St Brisbane

14th September 2016

Meeting notes by Ian Noble and Anna Mae Scott

1. The Patient Voice Initiative

The Patient Voice Initiative began in 2015 when a group of stakeholders from industry, academia and patient groups came together to discuss methodologies and approaches for eliciting the patient perspective on the value of medicines. As a result of these meetings a conference was organised in Sydney aimed at increasing patient engagement in health technology assessment (HTA) in Australia. Following the conference, a committee was formed to action items generated from the workshops.

The Patient Voice Initiative is Co Hosted by Rare Cancers Australia & Community and Patient Preference Research Pty Ltd (CaPPRe)

For more information about the Patient Voice Initiative – see page 4.

2. Background to the Brisbane meeting

The meeting in Brisbane is an extension on the 'Patient Voice Initiative', the objective of the day was to discuss ways of improving patient involvement in health technology assessment processes that are used in Australia by bodies such as the PBAC (Pharmaceutical Benefits Advisory Committee), MSAC (Medical Services Advisory Committee) and PLAC (Prostheses List Advisory Committee) for the reimbursement of new drugs, devices, procedures and prostheses. This included discussion on specific elements of the existing system e.g. patient experience in PBAC hearings.

The Brisbane meeting was a follow up to a meeting held in Sydney in February 2016 and was intended to make it easier for more patients and patient groups to be engaged. There were approximately 20 patients and patient advocates involved in Brisbane.

3. Meeting process

The meeting was split into 2 parts:

1st there was a down load of information, including:

- Top line review of HTA in Australia and PBS processes and the Pharmaceutical Benefits Advisory Committee (PBAC) (Ian Noble)
- Presentation given by Jo Watson (previously in Sydney February 2016) on consumer engagement in PBAC processes (Ian Noble)
- Direct experience from Jessica Bean (a patient with Cystic Fibrosis) of a PBAC hearing

2nd a workshop facilitated by Ian Noble and Jessica Bean on patient views of the current system and ideas on how best to improve patient involvement in the HTA process for listing of new drugs on the PBS.

The ideas generated were then compared and contrasted to ideas generated at the earlier meeting in Sydney, which took place in February 2016.

4. Use of the Brisbane workshop outcomes

The outcomes of the workshop are written up here and include a summary of ideas generated by patients and patient advocates on how to improve patient involvement in the HTA process. Additional notes were provided by Anna Mae Scott from Bond university who attended the meeting and those notes have been incorporated into this report. This output will be shared with the participants and also will contribute to another forum to be held in Canberra on 19th October 2016. The objective of the meeting in Canberra is to devise ways of converting ideas for improvement into action.

5. Workshop outcomes

Two groups brainstormed ideas and then synthesised their work to come up with 2 broad ideas/themes for improving the HTA process.

Group 1 Idea 1	Group 1 Idea 2
<p>The PBAC/Health Minister should commit resources so they can better inform the public about how to be heard in the drug approval/reimbursement process. The intention of this investment is to better inform the patient perspective in PBAC/Minister of Health decision making so that decisions are more relevant to patients:</p> <p>Elements to consider include:</p> <ul style="list-style-type: none"> • A dedicated website for patients and patient advocates on what the PBAC is, its processes, how to be involved and comprehensive linkages with patient interest / advocacy groups. • There is a need for earlier access points in the process for patients (10 weeks prior to PBAC meeting is too late) – more public awareness is needed. • As a reference it was mentioned by group 1 that ‘Australian Healthcare Quality Standards can be considered to guide such interaction. 	<p>We need ‘real’ quality of life information blended into PBAC decision making throughout the process. The ‘real’ refers to accounts of actual patient experience in a way that is helpful to the PBAC decision-making. A great example given was the talk given by Jessica Bean on her treatment journey as a person suffering with Cystic Fibrosis.</p> <p>Elements to consider include:</p> <ul style="list-style-type: none"> • Evidence generated directly from patients • There needs to be funded research by Government on what matters most to patients • Sponsors of clinical trials should be encouraged to include outcomes that matter most to patients • There needs to be more formal surveys of patients for the drugs going through the PBAC process – and much earlier • The evidence generation should be independent and separate funding should be provided.

Group 2 Idea 1	Group 2 Idea 2
<p>Education: There is a need for information and awareness of the system for patients and doctors of:</p> <ul style="list-style-type: none"> • Patient advocacy groups • Clinical trials • PBAC/PBS websites that are patient friendly • More information on processes for hearings etc. in plain English to encourage patient engagement. <p>Improve existing consumer PBAC submissions:</p> <ul style="list-style-type: none"> • Provide more emphasis on qualitative evidence • Provide more resources for PBAC consumer reps • Feedback must be made available to patients and patient groups on their submissions (to provide education and scope of continual improvement). 	<p>There is a need for a Website:</p> <ul style="list-style-type: none"> • Separate consumer submissions website • Feedback about the value of information in consumer submissions (learn and improve) • Funds for awareness campaigns to promote the website and value of consumer submissions • Plain English / lay friendly information videos (not written documents) and in other languages too • More resources available to do this all well • Include quality of life survey information on the website to accompany submissions

6. Other points that were raised in conversation / general themes.

- More transparency of processes, decision making and outcomes are needed
- There is a clear need for feedback loops
- More guidelines for patient are needed
- PBAC hearing process could include more information to assist patients and government participants
- Clinical trials and surveys need to be more patient relevant - patients should be included in the design of such trials / surveys.
- PBAC needs to be more proactive to reach out to citizens in order to get them more involved
- No need to reinvent the wheel on everything; there are many examples of 'doing more with patients' in other settings i.e. Scotland (SMC), Canada (CADTH) and England (NICE) as examples.

It was also noted that HTAi has an interest group focused on patient input and the attached link may be a useful resource for patients and patient advocates as it includes an outline of working models used in other countries to improve patient voice in health decision making. <http://www.htai.org/interest-groups/patient-and-citizen-involvement/resources/for-patients-and-patient-groups.html>

7. Conclusion

It was acknowledged that there were significant overlaps in the type of ideas generated by both groups for improving patient involvement in the HTA process. Additionally, when the outcomes of the Sydney meeting were shown (after the workshop), it was noted that many of the ideas generated in Sydney resonated with participants in Brisbane and there was broad agreement with Sydney outcomes.

Further information on the Patient Voice Initiative:

Steering Committee

Richard & Kate Vines RCA

Jessica Bean Patient Advocate

Simon Fifer & Laurie Axford CaPPRe

Todd Stephenson Janssen

Nathan Walters Johnson & Johnson

David Pullar & Carlene Todd Roche

Zarli French MSD

Industry Sponsors have provided funding to support the initiative

Johnson & Johnson, Janssen, Roche, MSD, Sanofi, Amgen, Pfizer, Bayer, BMS, Novartis, CaPPRe

Agenda:

Brisbane Satellite Meeting

Date: 14th September 2016

Address: Next Hotel, 72 Queen St Brisbane

Time	Topic	Speaker
9.30am	Welcome	Jessica Bean
	Objective of the meeting	Jessica Bean & Ian Noble
9.40 am	What happened at the Sydney meeting?	Ian Noble
9.45 am	Introduction to health technology assessment (HTA) in Australia	Ian Noble
10.15 am	HTA in practice - insights from a PBAC Hearing	Jessica Bean
10.30 am	Questions & Discussion	All
10.45 am	<i>Morning Tea</i>	
11.00 am	Workshop	
	A Patient Voice in HTA Decision Making What do you want to see?	Ian Noble
12.30 pm	<i>Lunch & Networking</i>	
1.15 pm	Next Steps	Ian Noble
1.30 pm	Close	Jessica Bean