



'Patient Voice' Meeting

20th September 2016

Cullen Hotel, 164 Commercial Rd PRAHAN Melbourne

Meeting notes by Ian Noble and Janney Wale

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 5.

2. Background to the Melbourne meeting

The meeting in Melbourne 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 Melbourne 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 17 patients and patient advocates involved in Melbourne.

3. Meeting process

The meeting was divided 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 experiences from Geoff Nyssen (a patient with multiple myeloma) and Jessica Bean (a patient with Cystic Fibrosis).

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 Melbourne 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 also provided by Janney Wale who attended the workshop representing the HTA_Aus Think Tank and these have also been incorporated in this summary of the workshop outcomes below. 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

Three 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>Need to develop a framework that allows effective timely and appropriate communication between PBAC, patients and medical professions:Elements include:</p> <ul style="list-style-type: none"> • Public summary documents and guidelines in plain language • Advocates to facilitate ‘conversation’ – to help patients tell their stories • Case studies as a guide for how the framework has worked well – success stories/examples • Development of best practice guidelines for consumer involvement in HTA/PBAC process • Training of advocates to assist them to become ‘experts’ in informing the PBAC • Involve consumers in all consumer hearings, including PBAC having access to a consumer groups/advocates database for consultation • Need feedback loops for allowing a two way conversation between PBAC and patients • Ongoing review and evaluation of PBACs own processes • Liaison points for consumers – needs resourcing / personnel / \$\$ to engage properly with patients 	<p>Database of upcoming/current clinical trials (and their results) that will be assessed by the PBAC as part of the PBAC submission process:</p> <p>Elements include:</p> <ul style="list-style-type: none"> • Earlier consumer feedback on the clinical trials used in the process (years before the PBAC submission date) • Transparency around the process and timelines • Education around trials and success stories • Medical professionals to be made aware of the current and upcoming trials and encouraged to openly discuss clinical trial options

<p>Group 2 Idea 1</p>	<p>Group 2 Idea 2</p>
<p>Improve the process for patients and patient groups:</p> <p>Elements include:</p> <ul style="list-style-type: none"> • Easier for patients to access information e.g. a section for patients on the DOH website • Greater representation of patients on HTA committees, both in type and number • Should consider a separate ‘consumer committee’ • PBAC to be more proactive in informing patients about process maybe through other health process/avenues • Current alert system could be tailored to send notifications • Current submission form at 10 weeks prior (publication of the agenda) needs an overhaul • Allowing people to present in a variety of ways as it is hard to do in just through one process, especially if the patient/advocate needs to be there in person • Weighting of criteria that are important to patients • Better knowledge of what ‘patient evidence’ is valuable 	<p>Improving the content of submissions:</p> <p>Elements include:</p> <ul style="list-style-type: none"> • Mandate for submissions to include measures/outcomes that are important to patients (NOT just clinicians) • The whole evidence generation process needs to be integrated from the beginning of the trial process • Patients need to be involved at the trial level in determining what is relevant and important

<p>Group 3 Idea 1</p>
<p>Make the patient central to the decision making process at every stage:</p> <p>Elements include:</p> <ul style="list-style-type: none"> • More communication and research (focused on patients) • Better involvement and representation of patients within the PBAC and better transparency • By creating a patient Committee within the PBAC process • Changing the structure of representation within the PBAC ‘by and for’ patients • Develop more effective ways to involve people in the process • By developing a framework plus guidelines for patient involvement <p>This would be used to assess and compare technical, quantitative and qualitative aspect</p>

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

- There is a need to be able to ‘quantify’ individual stories. Stories can provide powerful evidence for what is important to patients but this does not ‘fit’ well within the current system, which focuses mainly on the results of clinical trials. Jessica’s story was powerful; her treatment had a profound effect on her quality of life, but her lung function did not change. Lung function was the primary outcome in the trials so on this measure the drug

failed, however in reality the drug has transformed her life, her energy levels were boosted massively.

7. Conclusion

It was noted that the ideas and elements that were discussed in each group were similar between the groups; there was considerable overlap. Additionally when the results of the Sydney workshop were shared with the Melbourne meeting participants it was agreed that there were many similarities between Sydney ideas and Melbourne ideas. Such agreement bodes well for producing actionable outcomes at the Canberra meeting planned for October.

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

Meeting Agenda:

Melbourne Satellite Meeting

Date: 20 September 2016

Address: Cullen Hotel, 164 Commercial Rd PRAHAN

Facilitator Ian Noble

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

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