

'Patients are a virtue'

Is 'patient-centricity a verb or noun' and what can Medical Affairs do in this area ?



Highlights from APPA Education Meeting

Thursday 31st March 2022

hosted by award-winning Australian ABC medical reporter, Sophie Scott

How do we involve patients as key opinion leaders and stakeholders in medical affairs?

What does 'patient-centricity' mean to you?

- It's a buzz word
- Closer to a marketing term, than a culture or philosophy
- If we use it enough it will become a representation of what we do
- It has been overused to the point of diluting its intention
- **Person-centred care** is preferred
- It's about how we are at the centre of our own care

Where can patients have influence on the healthcare system?

- At every stage of discussion
- The registration and reimbursement process in Australia does not include a quantifiable measurement of the impact on patients
- Industry can be more courageous and we can engage better with patients
- Edition 19 of the Medicines Australia Code of Conduct includes changes that refer to how industry can engage with patients: appropriate people within organisations can provide information to patient groups to help them in their role (e.g. clinical trial information, pipeline information, education)
- Patient voice can have a huge impact on government
- Patients can work together with industry to reduce the access gap between registration and reimbursement

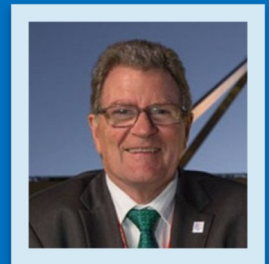
What are your thoughts on Medical Affairs involvement with patients?

- More engagement needed to bring together the data with the patient 'heart' story
- Industry performance should be based on the expected number of people treated (e.g. with lung cancer) in a year rather than revenue
- Our Code states that industry are the custodians of the information about the medicines we make and so we **should** be engaging with patients
- We have an opportunity to be part of this engagement, not to lead the engagement but to help the patient own their own disease and treatments

How can Medical Affairs become more involved with patients?

- Great for Medical Affairs to be involved with advisory groups from the beginning when people are being selected for studies, as patients can raise issues like reimbursement at that stage
- By having these types of conversation
- Engage them earlier, co-creation and co-design of clinical research
- Our Code does not prevent reimbursement of patients for their involvement in industry activities so long as it is commensurate with their contribution and is not inappropriately influencing
- Patient-centred care should be our end goal

With thanks to our panel:



Richard Vines
Rare Cancers Australia



Sophie Hibburd
Medicines Australia



Renza Scibilia
Diabetes Australia



Matt Britland
APPA

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Is 'patient-centricity a verb or noun' and what can Medical Affairs do in this area ?

Where does Medical Affairs currently sit with patient engagement in the co-design and co-creation of clinical trials and other person-centred initiatives in industry?

- We are not there yet but this should be our end goal
- There are hurdles and barriers in the way but there are processes within the Code to allow the reimbursement of patients for this
- This is critical as people can add the practical experience regarding trial design (e.g. tele-trials, test results, fatigue levels expected, lumbar puncture frequency, emotional impact, etc.) but this is not yet routine
- We have an ethical and moral requirement to get this right for patients

Selected Q&As from attendees:

How can we ensure true diversity in person-centred care?

- National tele-trial models
- Seek participants for trials outside of cities
- Change the way we approach trial recruitment
- Engage elders in ethnic groups to help recruitment
- Use novel tools to assist with accessibility for informed consent (i.e., use video, YouTube)
- Advertise via social media

Do Health Care Professionals think a person-centred approach is valuable?

- Some like it and some don't
- It is reflected in their engagement with the concept
- We can provide better education collaboratively about the benefits

What practical examples are there of how people can have a say in their healthcare (the person-centred approach)?

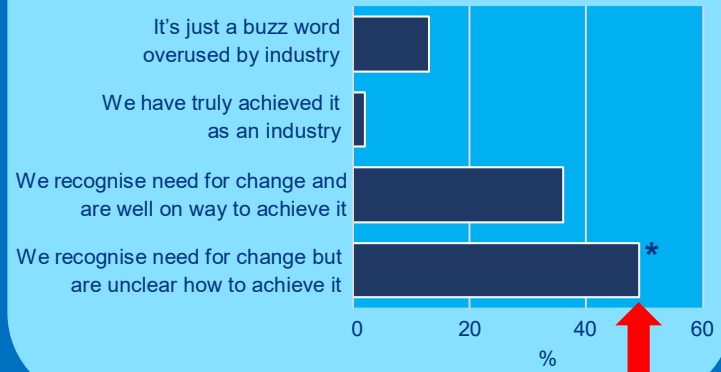
- Use a person in the community as a spokesperson that can use the 'right' language for the audience
- Go to the patient advocacy groups for advice

How can industry engage patients?

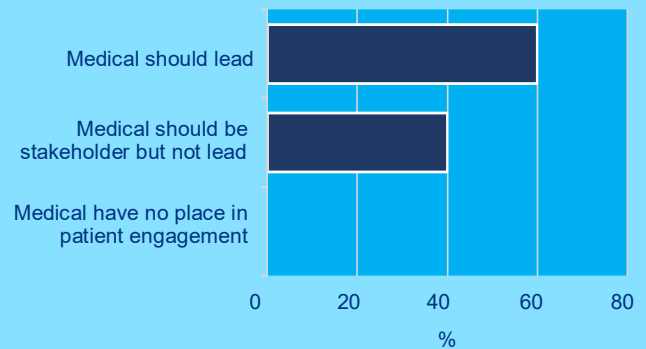
- Work more closely with patient advocacy groups
- Engage and connect with patient advocacy groups (we have mechanisms in the Code to do this)
- Help patients get together and connect and fund these activities
- Be courageous
- Have accountability for the terms we use
- Pursue academic research to support the benefits of patient engagement

1/2 felt industry recognise the need for change but is unclear how to achieve this*

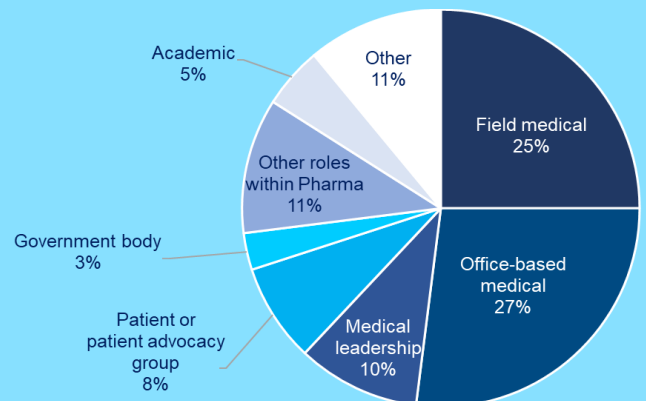
How do you feel about the word and concept of 'patient-centricity'?



Do you think medical affairs should lead patient engagement?



Who attended the webinar?



Would you recommend this webinar to a colleague?
Yes (n=35, 100%), No (0%)

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Selected quotes from the panel:

- "Patient experience is the lens through which you view the spreadsheet" - *R Vines*
- "I genuinely believe that people using the health system and living with health conditions have a place at every stage of discussions" - *R Scibilia*
- "We are able to make engagement [with patients] better and stronger" - *S Hibburd*
- "It's not about a revenue target. It's not about 'How do I get this drug from bench to bedside?'. It's about 'How do I make this person whole?'" - *R Vines*
- "Nothing about us without us" - *R Scibilia*
- "If there is no power to influence, then it is just pure tokenism" - *R Scibilia*
- "One of the incentives of having patients on this journey though is the patient voice which is hugely important" - *M Britland*
- "Nothing is more compelling if you are talking about changes to the system than a real life patient experience being presented by that patient to the decision maker" - *R Vines*
- "When you confront the world with the needs of a person who is an Australian citizen who has rights and aspirations and hopes, it is infinitely more compelling than presenting them with a spreadsheet" - *R Vines*
- "We have an opportunity [with HTA reform] to have greater patient involvement and it is something that we are strongly advocating for" - *S Hibburd*
- "[Medical Affairs] are here to help the patient own their own disease and their treatments" - *M Britland*
- "We all want the quality use of medicines and we've all realised that if we want to achieve this we need to put the patient there and listen to them and talk to them" - *M Britland*
- "Ask for us to 'feed in' sooner, so we are part of the design process...rather than 'feed back'" - *R Scibilia*
- "Consult early, consult often" - *S Hibburd*
- "If you think there are barriers that need regulatory or legislative change and you need advocates to work with you to do that, let's do it together...work with us" - *R Vines*
- "I challenge everybody to innovate and disrupt in this industry. Yes - compliantly, but disrupt - what's your 'Uber' in your medical strategy? How are you really going to change what you do?" - *M Britland*

More about our chair and panel:

Sophie Scott

Award-winning journalist, author, Adjunct Associate Professor and Medical Reporter for the ABC with a focus on medical research and original journalism



Renza Scibilia

Well-known health advocate living with Type 1 diabetes, Renza is a member of multiple Patient Advocacy Committees



Richard Vines

Founder and chairman of Rare Cancers Australia, a patient advocacy group with a mission is to improve lives and outcomes for rare cancer patients



Sophie Hibburd

Head of Ethics and Compliance at Medicines Australia, Sophie is committed to helping with practical implementation of the Code of Conduct



Matt Britland

Current President of the APPA, Matt is an experienced medical affairs leader and Medical Director at Amgen



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Thank you for your survey responses:

What are some of the opportunities that Medical Affairs can pivot into for patient engagement?

- Re-think the clinical trial recruitment process and seek input from patients much earlier on how to make this a better experience
- Early engagement to influence patient-relevant outcome measures, supported by clear company guidelines for working with patients
- Work with market access colleagues to influence endpoints in clinical trials
- Engage patient organisations and advocacy groups to understand barriers and unmet clinical need and then engage with facilitators to identify and access strategies to overcome the barriers and address the unmet needs
- Collect qualitative data to complement quantitative data
- Use innovative ideas like social listening, participate in open innovation forums like Wazoku
- Have early scientific conversations with patients to identify issues with their medicines, to identify questions to be addressed by new clinical trials and to help select appropriate outcome measures
- By facilitating clinical research and becoming involved with patient familiarisation programs
- Set up year-round patient steering committees via online platforms with quarterly face-to-face meetings with a stakeholder (e.g. Swipe Health)
- Applying principles of the Code of Conduct while not over-interpreting them

Does Medical Affairs need to be part of the patient-centric movement? And why?

- Absolutely, Medical Affairs is a stakeholder in the goal to enhance quality use of medicines
- Yes, as Medical Affairs is involved through all stages of drug development and beyond where they are involved in optimising the use of the medicine
- Every function has a role to play and they need to be strategic, considered and coordinated so the patient group is connected seamlessly along the journey from discovery to delivery and beyond
- All parts of an organisation need to be aligned but Medical Affairs can steer the alignment
- Yes, as one of the key pillars in the ethical use of medicines and as a source of accurate and balanced information to help mitigate against misinformation and disinformation
- Yes, as they are focused on the science and quality use of medicines versus the commercial KPIs and are more attuned to the patient and health care professional support
- Yes of course. Why—because we care about people and their health. It's about caring and ideally curing

How can the pharmaceutical industry become patient-centric in a real way? Any learnings from the past?

- Create patient advisory boards and engage with patients to understand their issues with how therapies are delivered to them (from bench to bedside) and their unmet needs
- Reach out and talk with consumer organisations and patient advocacy groups
- Include patients in all projects that will involve patients
- Take patient advice on board and if not, explain why not so they feel their input is valued
- Through dialogue and shifting focus towards patient-oriented objectives
- Move from 'patient-centricity' to 'open pharma'
- Bring patients in house (digital or physical)
- Champion the phrase "nothing about me without me" and look at how other industries have engaged the customer voice
- Address the mistrust and cynicism around the Pharma industry by becoming more transparent
- Partner with patients throughout the journey from trial design to reviewing a CMI: co-create and co-design
- Learn from best practices from stakeholders in the past as we've been patient focused for years

Who is APPA?

The Australian Pharmaceutical medical and scientific Professionals Association (APPA - <https://appa.net.au/>) is the representative association for Medical Affairs in Australia and is dedicated to promoting excellence in pharmaceutical medicine through professional development, networking and advocacy. APPA is an association of Medical Directors, Medical Advisors and Medical Scientific Liaisons working within Medical Affairs departments of Australian pharmaceutical companies.

Our mission - to drive the evolution of the Australian Medical Affairs profession and thereby improve Quality use of Medicine (QUM) for Australian patients.