7th Annual Patient Centricity & Engagement Conference

Demonstrating the value of effective patient engagement
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Summary of key themes

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Key themes from the conference

Trust in ‘institutions’ is declining – people seek information from sources they feel emotionally connected to, and consequently the most influential channels are changing.

Long-term partnerships between industry and patient communities are recognized as the most appropriate way to build trust and strong relationships, but there are still challenges – partly due to compliance. Ongoing open discussions can manage expectations and identify ways to resolve challenges.



Individual voices on social media which offer an emotional, personal connection (often peers with similar lived experience) are seen as more relevant than traditional sources of information.

Patient involvement in HTA is evolving rapidly, but the opportunities need clarity from regulators, and patients and PAGs need guidance and training to enable their effective engagement.

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Key: HTA, health technology assessment; PAG, patient advocacy group.

Key themes from the conference

- Investing in long-term partnerships with the patient community is the most effective way to build respected relationships, rather than one-off projects
- Industry has started to adapt processes to support better patient engagement which is welcomed by patient advocates
- Society now expects a more empathetic approach to healthcare, and clinical trials, and healthcare systems and companies need to adapt
- AI offers new opportunities to support communication – making it easier to provide tailored content, on demand, which can help build trust

"Being a patient feels like loss of control. Please reduce complexity and listen to us. Not all patients are the same, be flexible, and consider the needs of different groups. And also please make patient engagement feel like fun for us!"

– Breast Cancer Patient Advocate

"What if the biggest barrier to patient engagement is each of us individually – what if we ask ourselves what we can do to change things?

Start with a small project, find cross-functional partners, use existing data, and measure outcomes."

– Medical Affairs Director, global pharmaceutical company

Key: AI, artificial intelligence.

Clinical trial recruitment challenges

Barriers to clinical trial participation include lack of awareness, lack of trust, and practicalities such as location of trial sites

85% of trials fail to retain enough patients, 66% of trial sites don't recruit any patients

Medidata

How can these be addressed?

Explore what drives these barriers	Empathy in all interactions will help, especially in face-to-face interactions with patients before and during trials, across the whole healthcare team
Respect participation	Provide feedback, and be transparent with patients (e.g. provide lay summaries of trial data, developed with patient input)
Foster trust	Patients and caregivers need to feel empathy, feel heard and listened to, but this looks different to different people – tailored approaches are required based on an understanding of varying needs e.g., different generations, education, experience, geographies
Recruitment	Understanding communities and engaging at the right level is key – which might mean working with local connections to reach closed peer support groups which aren't on open social media channels)
Clinical trial design and recruitment strategies	Bring patients and HCPs together to input on study design; consider holistic and emotional health support which demonstrates understanding of non-clinical patient need; consider needs of people with co-morbidities or other additional needs to enable access to a broader target population

Key: HCP, healthcare professional.

How should we respond to the evolving environment?

- How we communicate with patient communities needs to evolve in the digital age
- Influencers are connected; they produce authentic content and present a value that people recognize and relate to. We can work with them, and learn from them, to communicate accurate information
- Information needs to be provided in a relatable way, and communities need support to understand how to 'fact check' information, and sources
- There is a need to increase awareness of gender bias to inform how care is managed – according to some sources HCPs are more likely to talk to female patients than male patients about holistic & emotional support



"There has been an erosion of trust in institutions and change in how people seek and receive information... 43% of UK adults struggle to understand health information"

IPSOS

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Key: HCP, healthcare professional.

Patient involvement in HTA is becoming more systematic, and society expects it, but how meaningful is it?

- Current HTA systems have limitations and payers don't often have direct interactions with patients, so they may be less familiar with lived experience
- The new EU HTA process for Joint Clinical Assessment is a very positive step, but patients need structured involvement and training to support them, and clarity on how feedback will be shared. Clarity is also needed around conflict of interest
- Plain language summaries being made available in the HTA process would support broader, more effective patient involvement. Health Technology Assessment International (HTAi) has developed a plain language summary template as a guide.
- Too often, the 'value' of treatment still doesn't include the patient or caregiver perspective – we need to recognize that 'fit for purpose' evidence might not be randomized clinical trial data
- Qualitative Patient Experience Data should be considered as part of value assessments – industry has an important role in helping to create robust data, but companies seek clearer guidance on what to include in submissions



"Diversity is being invited to the party, inclusion is being invited to dance"

– Jose Dias, BMS

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Key: HTA, health technology assessment.

“Ensuring a diverse trial patient population is scientifically correct and makes business sense.”

Medical Affairs Leader, global pharmaceutical company

