

THE ECOSYSTEM OF EVIDENCE

Lessons learned in the pandemic era and future challenges

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Improving patients' & consumers' involvement in healthcare decisions



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No financial conflicts of interest.













EXPERIENCE CAN JUST MEAN MAKING THE SAME MISTAKE WITH INCREASING CONFIDENCE.



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THINGS GOT TENSE FOR THE TOWNSFOLK WHEN THE THIRD META-ANALYST GANG RODE INTO TOWN-



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Quality & transparency issues with the interventions



* Reporting on interventions: TIDieR Checklist (via EQUATOR Network).

Hoffmann et al (2014). DOI: 10.1136/bmj.g1687



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"Where the outcome is <100/1000, pictographs were better understood and processed more quickly than bar charts, particularly if the difference between event rates was small...However, for more common outcomes (>100/1000), bar charts were better, possibly because the icon arrangement was more complicated. In addition, the role of shading in processing the part-towhole relationship of icon arrays is still not well understood."



Trevena et al (2013). DOI: 10.1186/1472-6947-13-S2-S7



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Analysis 5.1. Comparison 5 Participation in decision making, Outcome 1 Participation in decision making - all studies.

Study or subgroup	Decision Aid n/N	Usual Care n/N	Risk Ratio M-H, Random, 95% Cl	Weight	Risk Ratio M-H, Random, 95% Cl
Auvinen 2004	31/103	73/100	5 <u>000</u> 5	13.89%	0.41[0.3,0.57]
Davison 1997	3/30	10/30 🗲		2.62%	0.3[0.09,0.98]
Dolan 2002	7/43	6/43		3.48%	1.17[0.43,3.19]
Kasper 2008	6/134	10/139		3.6%	0.62[0.23,1.66]
Krist 2007	20/196	14/75		7.05%	0.55[0.29,1.03]
Legare 2011	26/81	24/70		10.33%	0.94[0.59,1.47]
Legare 2012	58/163	65/165		14.99%	0.9[0.68,1.2]
Man-Son-Hing 1999	16/137	23/146		7.59%	0.74[0.41,1.34]
Mathers 2012	8/92	16/77	· · · · ·	5.08%	0.42[0.19,0.92
Morgan 2000	25/86	39/94		11.42%	0.7[0.47,1.05]
Murray 2001a	5/57	4/48		2.37%	1.05[0.3,3.7]
Murray 2001b	5/94	6/95		2.76%	0.84[0.27,2.67]
Sawka 2012	4/37	9/37		3.05%	0.44[0.15,1.32]
Smith 2010	3/357	0/173		0.47%	3.4[0.18,65.5]
Vodermaier 2009	14/53	16/54		7.36%	0.89[0.48,1.64
Whelan 2003	6/80	12/91	·	3.93%	0.57[0.22,1.45]
Subtotal (95% CI)	1743	1437	•	100%	0.68[0.55,0.83]
Total events: 237 (Decision Aid), 3	327 (Usual Care)				
Heterogeneity: Tau ² =0.05; Chi ² =2	3.59, df=15(P=0.07); I ² =3	6.42%			
Test for overall effect: Z=3.74(P=0))				

Stacey et al (2017). Decision aids for people facing health treatment or screening decisions. (Cochrane) DOI: 10.1002/14651858.CD001431.pub5



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"Trickle down" thinking is a trap.



Mhaimeed et al (2023). Shared decision making with black patients: a scoping review. DOI: 10.1016/j.pec.2023.107646



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Lessons learned in the pandemic era and future challenges





"In May, 1754, a complaint as to the meat and beer was judged to be unfounded. The complaining patients were severely reprimanded, and ordered to have toast and water for a week."

Porter (1990). In The Hospital in History, pp 149-78.













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We need to invest seriously in multiple levels of regularly updated, evidencebased patient information & its popularisation.

Note: Oxman & Paulsen (2019). Who can you trust? DOI: 10.1186/s12911-019-0772-5







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Rights & "patient journey" approach, underpinned by literature reviews, patient interviews, & focus groups

	[Phase]	[Phase]	[Phase]
Daily & social life			
Coping/managing the disease			
Psychological impact			
Knowledge level			
Decisions			
Clinical perspective			
Health professionals			

Bastian et al (2010). [German]

https://www.egms.de/static/en/meetings/ebm2010/10ebm065.shtml







We need methods for the "consumer" involvement role in policy decisions, & "patient-centeredness" measures for outputs.



Note: Mrklas et al (2022) (Systematic review of current measures)

DOI: 10.1186/s12961-022-00938-8

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Not just skills – power dynamics, subcultures, & norms need to evolve.





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"[We] have made far more progress in cataloguing cognitive biases than in finding ways to correct them."

Lilienfeld et al (2009).

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DOI: 10.1111/j.1745-6924.2009.01144.x







Thank you!



Newsletter, Living With Evidence: https://hildabastian.wordpress.com/



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