Current Approaches and Challenges for Patient Engagement in Real-World Studies: a Targeted Literature Review

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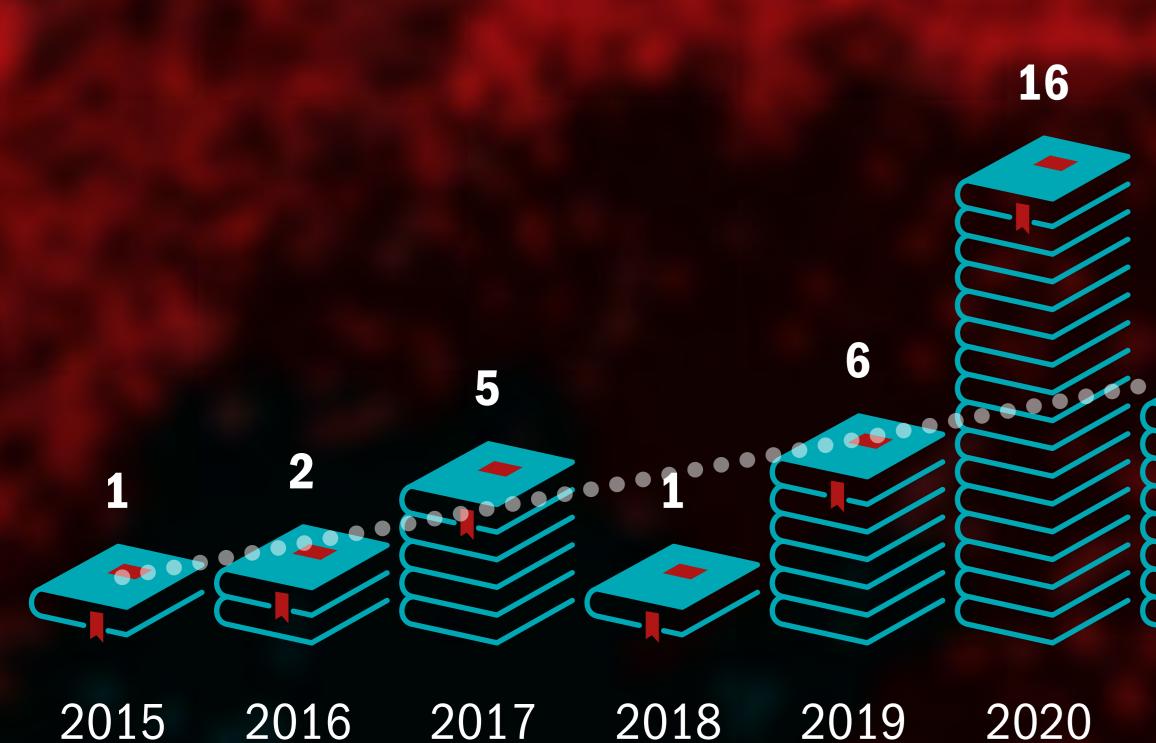
BACKGROUND

 The importance of a patient's perspective during the development of devices, medicines, and procedures

used in healthcare is increasingly being recognised to ensure that decisions reflect the preferences of patients¹



Figure 2. Records included in the analysis by publication year



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OBJECTIVE

20

65%

- However, true patient engagement in development processes, including clinical trials and real-world studies (RWS), has not yet been fully realised

Reviews

4%

Figure 3. Topics of patient engagement identified in the included records

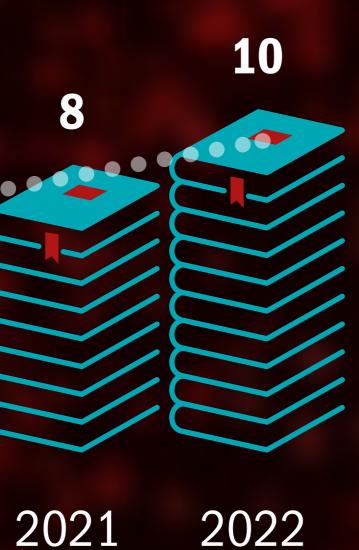
Patient engagement as research paticipant(e.g. measuring PRO outcomes)

Patient engagement in study design, co-authoring, or shared decisionmaking

> Other (e.g. framework design, future research recommendation)

CONCLUSIONS

- patient participation are limited



18%

To assess current approaches to patient engagement in RWS, and to identify challenges to inform future directions using a targeted literature review

METHODS

 We performed an EMBASE search (all dates up to and including January 2023) to identify English language publications concerning real-world evidence (RWE) that focussed on patient engagement

Figure 4. Challenges in patient engagement in RWS identified in the included records

> Exclusion of the patient voice from the design process

No consensus about how to operationalize the need for patient engagement

> Inconsistent and fragmented

patient engagement

Discussion or review on patient engagement as a general topic

• Based on our analysis, most current RWS engage patients for PRO measurements only, while other approaches for active

• Initiatives, such as the Patient Engagement Management Suite², are needed to provide clear guidelines or frameworks for the involvement of patients in RWS design, study participation, and guidelines or frameworks processes³

• Involving patients in the design of RWS increases patient engagement and may result in higher quality data

2. Feldman D, et al. Res Involv Engagem. 2021;7:57

REFERENCES

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Best practices for capture and integration of PROs are not yet defined

No accepted master framework for systematic patient involvement in RWS design and conduct