

BARRIERS TO DISSEMINATING INFORMATION ON CLINICAL TRIALS-PATIENTS' ORGANISATION PERSPECTIVE

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IN THIS PRESENTATION

- Barriers to provision of general educational information on clinical trials and possible solutions
- Barriers to provision of information on individual clinical trials

EDUCATIONAL INFORMATION ON CLINICAL TRIALS

- Barriers: emphasis on more “urgent” issues; means of delivery; level of language and link to medical statistics; quality of the text/narrative; availability in a local language; attitude of deliverers, “unfortunate” link to maths; plethora of sources where one can get “lost”; new resources need to prove they are trustworthy; who provides the information;
- Possible solutions: more “face-to-face”, disease specific lay trainings/courses; webinars are good, but!; involve local, respected institutions and CBOs to endorse (particularly academia); mobile device friendly; Q&A apps; do the homework for targeted distribution;

INFORMATION ABOUT INDIVIDUAL CLINICAL TRIALS

- Barriers: often available only in English and on US websites; sites often user unfriendly; information often provided by the sponsor or the medical professional still with only rare possibilities to speak with a peer;
- Possible solutions: involve the CBOs; make sure that they participate in the study protocol review; include them on the DMC; make available a presentation of the study in local language and publish on the hospital or CBOs' websites; make sure the results are published in a patient friendly local language (on time);

THANK YOU!

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