



A Survey of Global Resources for Clinical Trial Awareness and Education

As global recruitment strategists, we are often asked, “How do you recruit patients in [country]?” Of course the expected factors are taken into account – regulations, indication, age, standard of care, competing studies, etc., but the high-level research culture of a country or region also shapes approach. To successfully leverage the value proposition of a specific study, it needs to be considered in the context of the prevailing mindset, awareness level, and receptivity to clinical research in general. This goes beyond well-established cultural norms into policies and politics, stakeholder activities, recent events, and media influences.

The emerging focus on patient centricity may help foster a culture of research. More than ever before, clinical trials are being designed and executed with the participants’ needs and interests in mind, not just the researchers’. Being able to explain how patients’ priorities have been incorporated into the design of a protocol is an important step in increasing the likelihood of a patient choosing to participate in a specific study when they are in need of a treatment option, but these efforts have to be collectively communicated on a broader scale to start creating mindsets that are more positive towards clinical research participation in general.

It is well understood that the moment when you may be eligible for a study is not an ideal learning opportunity for an introduction to the basics of clinical research. Clinical research education needs to be provided not only as a precursor to participation in a specific study, but as a larger public health effort to dispel misconceptions of clinical research and prepare patients and their families to make educated choices. Some have envisioned high school students learning about protocol designs and human subject protections in their science classes.

In the US, the FDA, patient advocacy groups, and industry groups, such as the Center for Information and Study of Clinical Research Participation (CISCRP) have had initiatives to educate and engage patients and healthcare providers in clinical research for a number of years. However, efforts like these to increase patient awareness and understanding of clinical research continue to struggle to gain momentum. It is encouraging to see new efforts, such as the Ok to Ask campaign in the UK, and the launch of the EU clinical trials registry similar to the ClinicalTrials.gov site. If more countries and regions look to adopt similar initiatives in the near future, perhaps these efforts can look to create synergies and share resources to help one another. There may also be opportunities for collaboration among current organisations that have common goals within their respective populations.

To examine the potential for this possibility, we sought to create a view to the global landscape of efforts and resources aimed at increasing general awareness and understanding of clinical research. We performed primary and secondary

research to identify organisations and initiatives supporting general clinical research education for patients and/or healthcare providers. Extensive online searches for clinical research education efforts and initiatives were performed for 60 countries. A total of 47 resources were identified in 37 countries, six of which are multinational. Each resource was categorised according to their primary function as one of the following: public resource, industry resource, registry, and awareness initiative. Public resources are those aimed at assisting patients, while industry resources are in support of healthcare providers.

No clinical research education resources were found in the following 23 countries:

- Afghanistan
- Armenia
- Austria
- Bangladesh
- Bolivia
- Cambodia
- Croatia
- Czechoslovakia
- Egypt
- Greece
- Guatemala
- Iceland
- Indonesia
- Ireland
- Mexico
- Nepal
- Nigeria
- Poland
- Romania
- Slovenia
- Turkey
- Uruguay
- Vietnam

Six multinational organisations were identified, including four in Europe:

Country	Public resource	Industry resource	Registry	Public awareness initiative
Europe Clinical Trials Register			X	
European Communication on Research Awareness Needs (ECRAN)	X	X		
European Clinical Research Infrastructures Network (ECRIN)	X	X		X
Europe Clinical Trials Register			X	
International Federation of Pharmaceutical Manufacturers and Associations (IFPMA)	X	X	X	
Pan African Clinical Trials Registry			X	

Of 60 countries, 13 (22%) have country-specific public resources, 19 (32%) have industry resources, 16 (27%) have registries, and just three (5%) have public awareness initiatives. Four active public awareness initiatives were identified: The Initiative to Promote Clinical Trials in Belgium, OK to Ask (UK), Aware for All (US), and Medical Heroes (US).

To get a sense for how well known these organisations may be among the populations they seek to support, we surveyed contacts in a selection of countries: Belgium, Italy, Russia, Brazil, Guatemala, Peru, India, China, Singapore, Ethiopia and Tanzania. Respondents were either native to the country they are living in, previously lived in a specified country, or have family still living in their country of origin. Although 70 per cent of respondents have some connection to the healthcare industry, 90 per cent were unaware of clinical trials resources in their country of origin.

Clinical Trial Education Resources

Country	Organisation/Initiative	URL
Australia	ANZCTR Australia New Zealand Clinical Trials Registry	http://www.anzctr.org
	Australianclinicaltrials.gov.au	http://australianclinicaltrials.gov.au
Belgium	The Initiative to Promote Clinical Trials in Belgium	www.theinitiative.be
	Dutch Clinical Trial Foundation	http://www.dctf.nl
Brazil	Aliança Pesquisa Clínica Brasil (Brazilian Clinical Research Alliance)	http://www.endocrino.org.br
	ABRACRO (Brazilian Association of Organizations Representative of Clinical Research)	http://www.abracro.org.br
Bulgaria	Bulgaria Drug Agency	http://en.bda.bg
Canada	Health Canada's Clinical Trial Database	http://www.hc-sc.gc.ca
China	ChiCTR	http://www.chictr.org
Cuba	RPCEC Registro Público Cubano de Ensayos Clínicos	http://registroclinico.sld.cu
Ethiopia	The East African Consortium for Clinical Research (EACCR)	http://eaccr.org
France	F-CRIN (French Clinical Research Infrastructure Network)	http://www.fcrin.org
Germany	German Clinical Trials Register	https://drks-neu.uniklinik-freiburg.de
Hungary	MKVT Magyarországi Klinikai Vizsgálatszervezők Társasága	http://www.mkvt.hu
India	Clinical Trials Registry India	http://ctri.nic.in
Indonesia	CRA Indonesia (Clinical Research Associate Indonesia)	http://craindonesia.wordpress.com
Iran	IRCT Iranian Registry of Clinical Trials	http://www.irct.ir
Japan	JMACCT's Japan Medical Association Center for Clinical Trials	http://www.jmacct.med.or.jp
	National Institute of Public Health	http://rctportal.niph.go.jp
	UMIN Clinical Trials Registry (UMIN-CTR)	http://www.umin.ac.jp
Malaysia	Clinical Research Malaysia	http://www.clinicalresearch.my
	Clinical Research Centre	http://www.crc.gov.my
New Zealand	The New Zealand Association of Clinical Research (NZACRes)	http://www.nzacres.org.nz
	New Zealand Clinical Trials	http://clinicaltrials.health.nz
Peru	Oficina General de Investigación y Transferencia Tecnológica (OGITT)	http://www.ins.gob.pe
Philippines	Philippine Health Research Registry	http://registry.healthresearch.ph
Portugal	Portuguese Clinical Research Infrastructure Network (PtCRIN)	http://web.fcm.unl.pt
Puerto Rico	PRCTRC Puerto Rico Clinical & Translational Research Consortium	http://prctrc.rcm.upr.edu
Scotland	Scotland Clinical Trials	http://www.scotlandclinicaltrials.co.uk
Singapore	Health Sciences Authority	https://eservice.hsa.gov.sg
South Africa	South African National Clinical Trials Register	http://sanctr.gov.za
South Korea	KNECT Korea National Enterprise for Clinical Trials	http://www.konect.or.kr
Spain	AGENCIA ESPAÑOLA DE MEDICAMENTOS Y PRODUCTOS SANITARIOS	http://www.aemps.gob.es
Sri Lanka	Sri Lanka Clinical Trials Registry	http://slctr.lk
Sweden	Swedish Clinical Research Infrastructure Network (SweCRIN)	http://www.swecrin.se
Switzerland	Swiss Clinical Trial Organization	http://www.scto.ch
Thailand	TCTR Thai Clinical Trials Registry	http://www.clinicaltrials.in.th
The Netherlands	trialregister.nl	http://www.trialregister.nl
United Kingdom	UKCRN UK Clinical Research Network	http://public.ukcrn.org.uk
	INVOLVE's InvoNET	http://www.invo.org.uk
	NHS National Institutes for Health Research Clinical Research Network	http://www.crn.nihr.ac.uk
United States	CISCRP	http://www.ciscrp.org
	clinicaltrials.gov	http://www.clinicaltrials.gov

With nearly 50 organisations throughout the world, and potentially more not identified by this informal survey, all seeking to create awareness among patients and healthcare providers on clinical research, opportunities for collaboration, sharing of best practices and synergies should be examined.



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