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Bringing Patient Voices into Clinical Research : Challenges and Opportunities

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(OPEN)

BREAST CANCER SURVIVOR

PATIENT ADVOCATE

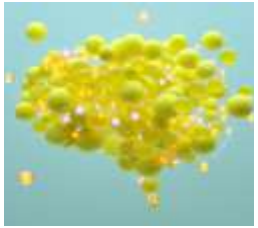
- Breast Cancer Survivor
- Caregiver to elderly parents and parents-in-law with multiple medical condition
- Patient Mentor with SingHealth Patient Advocacy Network (Founding Co-Chair)
- Member, ACE Consumer Panel, MOH
- Member (lay-representative), TRUST Data Access Committee, MOH
- Board Member, Alliance of Patient Organizations Singapore
- Member, Global Patient and Family Advisory Board, The Beryl Institute, USA.

Staff's view Patient's view

Why the patient and family's perspective is important

Why patient involvement?

Makes research more relevant & identifying outcomes that matter to patients/public



Broaden the pool of ideas to improve research

Help to spot blindspots in the research design and process.

Ensures the research & research materials are **patient friendly**

- defines what is likely to be acceptable to patient participants

Improves recruitment because the research is made more patient-friendly, with their needs and concerns addressed.

Improves communication of findings to participants and the world.

Ensures patients' needs, expectations and preferences are met!

What is the difference...

Patients as Research Participants

- Provider of data for research

Patients as Research Partners

- Help to shape research design, directions and implementation on what matters to patients

Discussion with patient partners at the TARIPH Centre, LKCMedicine

How patients can contribute to clinical trials

1. Patients can provide **insights into the disease burden**, the patient pathway, patient needs and preferences for clinical trials/research methodology.

2. Patients can provide **generic insights** such as assessing if the clinical visit schedule is too heavy and whether there should be transportation issues.

3. Patients can provide input on **study design**, including inclusion/exclusion criteria and endpoints; are familiar with the design of a clinical trial protocol and can co-create patient interview guides and plain-language summaries for clinical trial participants.

4. Patients have vocational backgrounds relevant to medicines development.

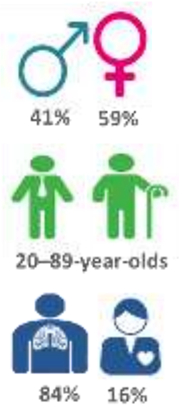
How-To guides for Patient Engagement, Patient focused Medicines Development, p10.
https://pemsuite.org/How-to-Guides/Patient-engagement-in-clinical-trial-protocol-design.pdf

Challenges : Why patients hesitate to participate in research?

What patients are telling us

Patient Voices in Respiratory Medicine Study

- N=460
- Survey conducted in English, Chinese, Malay Tamil



Interest in participating in clinical research

- 77% had not participated in clinical research.
- But 41% said they wish to participate.

Reasons for wishing to participate

- To help others
- Learn more about my condition
- Trust in my doctor

Reasons for not participating

- Inconvenience
- Uninterested

Challenges : What is stopping researchers?

Having another party on board makes things complicated.

I do not need patient contact for laboratory research

For clinicians – "I work with patients all the time. I understand what they need."

- Patients are usually ill. So they may not be able to contribute and will be frequently absent.

For researchers – I am a patient and caregiver too. That should be enough.

Not enough time and resources

My research is too complex for lay people

Not sure how to do it

The right attitude can transform a barrier into
a blessing, an obstacle into an opportunity or
a stumbling block into a stepping stone.

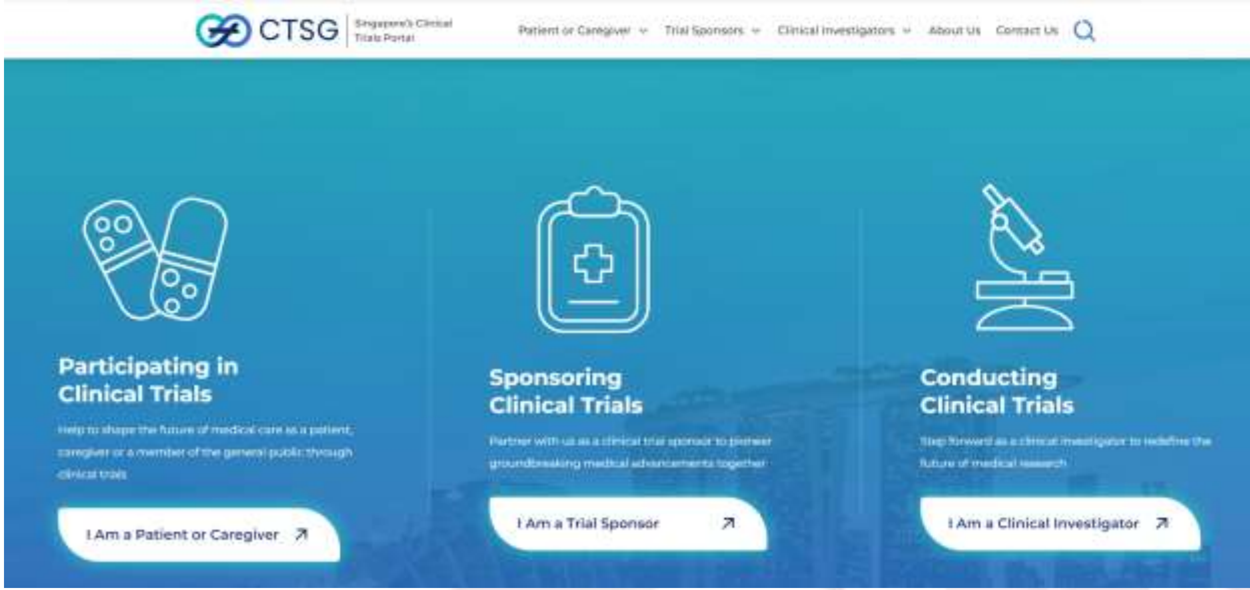
What needs to be done to bring patient voices into clinical research?

- Increase patient and public awareness and receptivity towards clinical research
- Capacity Building
- Capability Development
- Resources and processes to embed patient engagement into the organisation

#1 Increase patient and public awareness and receptivity towards clinical research

#1 Increase patient and public awareness and receptivity towards clinical research

- Making clinical research more accessible
- Public outreach on value of patient participation in research
- Engagement with patient advocates and patient organisations



Participating in Clinical Trials

Help to shape the future of medical care as a patient, caregiver or a member of the general public through clinical trials

Sponsoring Clinical Trials

Partner with us as a clinical trial sponsor to pioneer groundbreaking medical advancements together

Conducting Clinical Trials

Step forward as a clinical investigator to redefine the future of medical research

https://clinicaltrials.sg/

#2 Capacity Building : Growing Patient Engagement in Singapore

ACE
agency for
care effectiveness

SingHealth

National Healthcare Group
POLYCLINICS

NUHS
National University
Health System

Patient Engagement in

- Medical Research
- Healthcare improvement
- Patient safety
- Health technology assessment (HTA)
- Drug development and regulation
- Patient education

> 100 Patient Organisations

sapi Singapore Association of
Pharmaceutical Industries

SCRI
SINGAPORE
CLINICAL
RESEARCH
INSTITUTE

CoRE
Centre of Regulatory Excellence
@ Duke-NUS Medical School

ALLIANCE OF
PATIENTS'
ORGANIZATIONS
SINGAPORE
Patients Co-creating Healthcare

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LKCMedicine Office of Patient Engagement (OPEN)

OPEN Voices

LKCMedicine Patient Panel (>30 pioneer patient partners) to launch on 19 Nov 2024

Patient Engagement in Education

Partner with educators for NTU MBBS

OFFICE OF
PATIENT
ENGAGEMENT

Patient Engagement in Research

Partner with PIs in research projects

Partnerships

Build partnerships with patient organisations,

Capability Building

Capability building for patients, researchers and clinicians in Singapore and Asia

Research projects with patient-public involvement

Respiratory medicine – TARIPH Lung Patient Network

Family Medicine

Trust of AI in Medicine

Dementia

Enabler and Advocate for patient and public voices for medical research and education

#3 Capability Development

➡ **Patients , Family Caregivers, Researchers, Healthcare Professionals**

Capability Development– Patient Partners

Developing skills to communicate the patient perspective :

Example :

- Storytelling
- Patient advocacy and leadership skills.
- Understand the essentials of medical research and healthcare system.

Patients as Research Partners (PREP) Workshop

Role and Responsibilities of a Patient Partner

Understanding medical research and the research cycle

Communicating the Patient's Perspective

- LKCMedicine's **Patient as Research Partners (PREP) Workshop**
- SPAN's **Patient Advocates Communication Training (PACT)**
- ACE's **HTA Training Workshops** & **bite-sized learning modules**
- SAPI's **Empowering Patient Organisations: Navigating Healthcare Ecosystem, Economics, and Engagement**

Fostering the growth of the patient advocacy eco-system – growing patient support groups & patient organisations

Capability Development – Researchers & Healthcare Professionals

Training and education for those who engage patients in medical research and healthcare improvement.

E.g. Patient engagement best practices and tools, how to involve patients in research, patient-friendly communication skills (written & verbal)

Patient and Public Involvement and Engagement (PPIE) 101 Workshop

Other resources for researchers

How-To Guides for Patient Engagement

How-to Guide on Patient Engagement in Clinical Trial Protocol Design

CLINICAL TRIALS TRANSFORMATION INITIATIVE

CTTI Recommendations: Patient Group Engagement

October 2015

CTTI MISSION: To develop and drive adoption of practices that will increase the quality and efficiency of clinical trials

Clinical Trials Transformation Initiative. CTTI Recommendations: Patient Groups and Clinical Trials. Published October 2015. https://ctti-clinicaltrials.org/our-work/patient-engagement/patients-groups-clinical-trials/

PARADIGM

imi

Planning Patient Engagement

Raising awareness on managing competing interests in a multi-stakeholder environment:

Guidance to patients and engaging stakeholders

Pemsuite.org

#4 : Resources & Processes

Buy-in

Leadership support and buy-in. Identifying champions in the organization to drive patient engagement

Invest

Build infrastructure, mechanisms and budget ($$$)

Embed

Embed patient involvement into processes for sustainable patient engagement systems

Growing the patients’ voice

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Thank you