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ClinTrial Refer 2021 General Practice Roundtable Report June 2021





OUR VISION

A healthy Australia, supported by the best possible healthcare system.

OUR MISSION

To conduct research, educate and influence the healthcare system to achieve better health outcomes, improved patient and provider experience, greater equity and sustainability.

OUR GUIDING PRINCIPLES

Healthcare in Australia should be:

Effective
Accessible
Equitable
Sustainable
Outcomes-focused.

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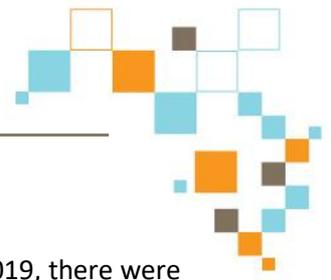
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CLINICAL TRIALS IN AUSTRALIA

Clinical trials form an important component of the Australian health care system. In 2019, there were over 1,800 ongoing clinical trials in Australia each year; with the majority of the \$1.1 billion of expenditure for clinical trials supported via international investment.

Clinical trials are an integral part of research and development and are fundamental to establishing:

- new treatments,
- new ways of using existing treatments,
- diagnostic tests,
- the safety and effectiveness of preventative or supportive interventions, and
- generating evidence for best-practice care.

Clinical trials are associated with improving outcomes for patients in terms of quality-of-life and survival, most likely due to the increased clinical surveillance associated with clinical trials and greater clinician adherence with evidence-based care. Clinical trials are an important way to support the development of new treatments and improving patient care.

In general, clinical trial activity in Australia is not tracked centrally in a consistent and comprehensive way. Instead, activity is tracked by multiple distributed and fragmented data registries, with no single data source capturing all clinical trial activity in Australia. This fragmentation can be attributed to the funding and sponsor landscape, as well as a lack of legislation requiring centralised registration or authorising central tracking.

Limited data also means that opportunities for policy approaches to increase clinical trial participation are currently not supported by a strong evidence base; ultimately limiting the patients' ability to access novel treatments in areas of unmet need. In addition, Australia is often viewed as less competitive than emerging markets on metrics of cost, timeliness of trial start-up, and the capacity to recruit the number of agreed trial participants. In 2020-2021, the Australian Commission on Safety and Quality in Health Care piloted the National Clinical Trials Governance Framework with the aim of cultivating the delivery of high-quality safe and respectful clinical trial services for improved patient outcomes.

While there is limited research available that identifies the success of specific recruitment and retention measures into clinical trials, barriers to trial participation have been identified as:

- Distance between a clinician's practice, or patient's residence and the nearest clinical trial centre; regional centres often lack infrastructure and workforce, including adequate specialist support to deliver standard chemotherapy treatments, and patients must travel to regional or metropolitan centres for trials.
- Affordability, out of pocket expenses associated with cost of travel to specialist centres and accommodation away from home, loss of income as a consequence of disruption to work
- Social disruption and lack of social support, convenience, need for family or friends to accompany them or look after families, properties, businesses.

The Australian Government 2021-22 budget has included \$6 million over 4 years to continue the Encouraging More Clinical Trials in Australia program which supports collaboration with jurisdictions



to grow the number of clinical trials run in Australia, while also removing red tape for industry and states and territories from the process. The continuation of the Encouraging More Clinical Trials in Australia program provides direct benefit to researchers, research institutions and trial sponsors, by facilitating more trials in Australia. It also ensures that our domestic research can culminate with trials in an Australian context, with Australian patients.

Patients and the broader economy will also benefit with local research leading to Australian made breakthroughs in health and medical innovation, improved health outcomes, and new sources of economic growth and employment.



CLINTRIAL REFER

ClinTrial Refer is an award-winning evidence based mobile app and website platform designed to simplify access and accelerate recruitment to current clinical trials. ClinTrial Refers user friendly search portal connects patients, clinicians and clinical trial units across various clinical settings.

First launched in 2013 for Haematology trials in NSW, ClinTrial Refer has expanded to cover trials in over 32 disciplines, across 700 sites in both Australian and international locations.

The ClinTrial Refer vision is to increase access to and participation in clinical trials research:

all patients, all trials, all doctors

ClinTrial Refer provides healthcare professionals and patients with a vital pathway to search for currently recruiting trials. The platform provides access to key information, such as a lay trial summary, key eligibility criteria, and trial location and site contact information. Trial data in the platform is current and comprehensive as it comes directly from participating trial units.

ClinTrial Refer delivers search results within seconds. No waiting to be contacted. Users can make immediate enquiries with the trial location and share results with their family or treating clinician for follow up.

The app is a knowledge management tool that has facilitated culture change and improved collaboration amongst clinicians. This has resulted in reciprocal cross referral - enhancing patient access to emerging therapies through clinical trial participation.

ClinTrial Refers digital footprint also ensures equitable access to emerging treatments for people in rural, regional and remote communities.

Healthcare services should be accessible, navigable and helpful in attaining comprehensive options to maximise the best possible outcomes. ClinTrial Refer is positively embracing digital health technology to facilitate a connected health care model that helps achieve this.

ClinTrial Refer is a not for profit owned by Sydney local Health district and South Eastern Sydney Local Health District.

Find out more about ClinTrial Refer [here](#).



2019 CLINTRIAL REFER ROUNDTABLE EVENT

In May 2019, ClinTrial Refer, in partnership with the Deeble Institute for Health Policy Research, Australian Healthcare and Hospitals Association (AHHA), held an invitation only roundtable and facilitated discussion that explored an improved role for general practice in clinical trial recruitment.

Participants included researchers, general practitioners (GPs), Primary Health Network leaders and consumers.

Through guided discussions using the World Café methodology, the day provided a platform for participants to share their experiences, knowledge and reflections of issues relating to clinical trial recruitment.

Discussion addressed how general practitioners can better access clinical trials, with themes around:

- Culture – organisational and individual attitudes and behaviours
- Politics – Policy and funding levers that can influence change
- Technology – opportunities to use technology to facilitate better outcomes

Participants also explored their motivators and barriers to clinical trial recruitment and identified those opportunities that helped facilitate GP engagement in clinical trial referral.

A copy of the report can be found [here](#).



2021 CLINTRIAL REFER ROUNDTABLE EVENT

Postponed in 2020, ClinTrial Refer and the Deeble Institute for Health Policy Research, Australian Healthcare and Hospitals Association have held a follow-up roundtable discussion in 2021 to explore:

- The value proposition of clinical trials in general practice; and
- How they can be better integrated into primary care

The roundtable provided a unique learning opportunity for participants, as well as providing space to ask questions, voice opinions and hear the thoughts of others.

Its objective was to re-innovate the way Australian general practitioners currently recruit into clinical trials through examining:

- The way in which clinical trials are currently integrated into the primary care setting and what this might look like in the future;
- The type of innovative thinking that will change the way that GPs interact with clinical trials;
- How health leadership should be encouraged to ensure that GPs and patients have user-friendly access to current clinical trial information;
- What needs to change in primary care in order to facilitate patient access and
- How could ClinTrial Refer bridge its service capabilities into the primary care setting to facilitate point of care access to current clinical trials for GPs and their patients.



18:30	Welcome Address
-	
18:40	Facilitator: Prof Alison Verhoeven (Chief Executive, Australian Healthcare and Hospitals Association)
18.40	ClinTrial Refer GP Roundtable 2019- Post meeting Report (review and key messages) and ClinTrial Refer update
-	
19.00	Speaker: Prof Judith Trotman (Co-inventor ClinTrial Refer) (Haematologist, Head of Department, Haematology Concord Hospital)
19.00	Facilitated Group Discussion: Clinical Trials Value Proposition: Why Refer? The Value of Participation
-	
19.20	Facilitator: Prof Alison Verhoeven
19:20	RACGP Role for Support: How can RACGP Support? What Relationships Need to be formed? How will it be operationalised?
-	
19:30	Speaker: Dr Jeremy Hudson (Chair of Dermatology, RACGP) Senior Lecturer, James Cook University. Clinical Director of the North Queensland Skin Centre
19.30	GP Survey Results
-	
19.40	Speaker: Christine Zahren Business Development Manager, ClinTrial Refer
19.40	Facilitated Discussion: Integration of Clinical Trials in Primary Care and the Role of ClinTrial Refer
-	
20:20	Facilitator: Prof Alison Verhoeven
20:20	Summary/Next Steps
-	
20:30	Meeting Close

Table 1: 2021 ClinTrial Refer roundtable event agenda



Q1. THE VALUE PROPOSITION OF CLINICAL TRIALS: WHY REFER?

KEY MESSAGES AND SUGGESTIONS

MEANINGFUL ENGAGEMENT

The successful implementation of research activities, including clinical trials, into general practice requires, where relevant, the contribution of general practice into designing, conducting and aiding the management of research. Involvement needs to be acknowledged and respected.

INFRASTRUCTURE

There are barriers to general practice undertaking research including clinical trials. Researchers need to ensure that recruitment and other related processes are designed to minimise disruption to clinical practice. This involves recognising that trial recruitment in general practice is 'different'.

To this end, researchers may need to consider bringing research infrastructure into the practice so that recruitment does not rely on clinicians identifying patients.

The RACGP supports the need for the development and adequate funding of infrastructure to support research participation by GPs, their practices and their patients.

VALUE

Effective and informed patient engagement around clinical trials was not considered compatible with the competing demands on GP time. The current MBS activity-based fee structure is seen as the main impediment to acquiring the detailed trial knowledge necessary for involvement in clinical trial research. The provision of tangible benefits to GP involvement in clinical trials and general practice workload was acknowledged.

CONNECTIVITY AND COLLABORATION

Clinical trials provide an opportunity for collaboration and reciprocity between hospital and primary healthcare research. There is potential to engage with under-represented areas of general practice including regional and rural areas. Telehealth has provided clinical trial opportunities for engagement of general practice in research activities including clinical trials.

DISCOVERY

It was recognised that successful clinical trials in general practice rely on trial activity being high quality, transparent, and discoverable for both general practice and patients; but that there is also a pressing need to identify clinical trial activity occurring in general practice more broadly in the first place.

CULTURE

While not specifically defined, the importance of formulating a coherent and communicable value proposition was discussed. In order for ClinTrial Refer to be seen as a valuable tool, there needs to be a stronger recognition of the value of primary care participation in clinical trials. The efficacy of the tool is of little relevance if the output of the tool (referral to a clinical trial) is not valued.



Q2. HOW CAN CLINICAL TRIALS BE BETTER INTEGRATED INTO PRIMARY CARE? A ROLE FOR CLINTRIAL REFER.

KEY MESSAGES AND SUGGESTIONS

INTEREST

The need for improving engagement with general practice is recognised by the research community. However, research and clinical trials are ‘not a traditional part of what general practice does’ and without ‘interest’ it will be difficult to get primary care clinicians and practice managers involved in clinical trial recruitment.

EDUCATION

Improving the integration of clinical trials into primary care will require recognising the need for education and ongoing support for research in primary care across the general practice pipeline. This will need to include consideration of the medical curricula, advocating for additional funding for research and for clinician support, and allocation of CPD points.

Clinical trial networks have some capacity to provide resources for designing and implementing clinical trials.

Other enablers could be identified by reviewing existing exemplar programs and projects in primary care. For example, the ASPREE (ASPIrin in Reducing Events in the Elderly) study.

BUSINESS MODELS

The shift towards larger corporate business models in general practice has had an impact on the autonomy of GPs to be able to participate in research and which has necessitated trial organisers implementing different approaches to trial recruitment.

Successful engagement with corporate practice has included communicating with executives at the state level and a slow approach to individual practices, payment to the practice for each identified trial participant, limited time commitment for clinicians and having participants met at the practice by trial researchers.

It was recognised that most corporate practices carry out internal research or will require a significant proportion of the awarded research funding for participation in outward facing research, including clinical trials.

The question of how corporates can be encouraged to engage more proactively in clinical trials was asked; and also whether there may be opportunities for ClinTrial Refer to liaise with corporate practice to ascertain which of them might have an appetite to work in the clinical trial space.

PRIMARY HEALTH NETWORKS

Appreciating that engagement between PHNs and general practice can be variable, it was noted that most PHNs are open to supporting general practice and their involvement in clinical trials.



Overall, PHNs can discuss research, have good links to Universities and often provide placements and support for students. PHNs collect a lot of data that is fed to the AIHW for public use. It was noted that there can be unrealistic expectations by general practice around what PHNs are allowed to deliver.

COLLABORATION

ClinTrial Refer allows clinicians and researchers to connect, form networks and collaborate and has been shown to facilitate the breakdown of silos between trial sites. A meaningful collaboration between ClinTrial Refer and relevant professional bodies, for example the Australian Clinical Trials Alliance (ACTA), the Australasian Association for Academic Primary Care (AAAPC), the RACGP and PHNs should be explored.

PRIVACY

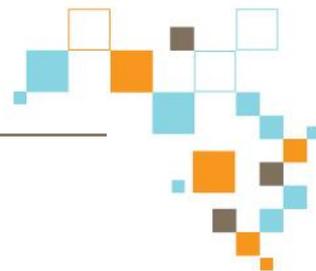
The privacy and wellbeing of potential trial participants is paramount. It was iterated that ClinTrial Refer is a tool that can be used to assist general practices and does not collect personal information of trial participants.

PATIENTS

The role of patient advocacy groups and their capacity to act as a conduit between patients and general practice was discussed.

It was noted that these not-for-profit groups are well connected to patient cohorts; who are often left without an avenue to clinical trials and looking for information, support and direction.

There is increasing recognition that patients are seeking a stronger voice in owning their own care journey and ClinTrial Refer provides an opportunity to connect patients who are looking to access clinical trials.



FACILITATOR



Adj Professor Alison Verhoeven:
Chief Executive, Australian Healthcare and Hospitals Association

Adjunct Professor Alison Verhoeven is the outgoing Chief Executive of the Australian Healthcare and Hospitals Association, the independent peak membership body and advocate for the Australian healthcare system and a national voice for universally accessible, high quality healthcare in Australia. Ms Verhoeven has broad experience in health, education, corporate governance and communications, and has worked in both the private and public sectors in Australia, the Asia-Pacific region, and Europe.

SPEAKERS



Professor Judith Trotman, MBChB, FRACP, FRCPA
Co-Inventor ClinTrial Refer
Haematologist, Head of Department, Haematology Concord Hospital

Professor Judith Trotman, Head of Department Haematology, Concord Hospital, Sydney is committed to ongoing recognition and promotion of both investigator-initiated and industry collaborations in clinical trials research. As a Board member of the Australian Clinical Trials Alliance (ACTA), as member of the Australasian Leukaemia Group (ALLG) Scientific Advisory Committee, and as principal investigator on several international clinical trials she has insight to the challenges and opportunities faced in clinical research. Professor Trotman co-developed ClinTrial Refer after recognising the central role of knowledge about currently recruiting clinical trials to promote collaboration in clinical research.



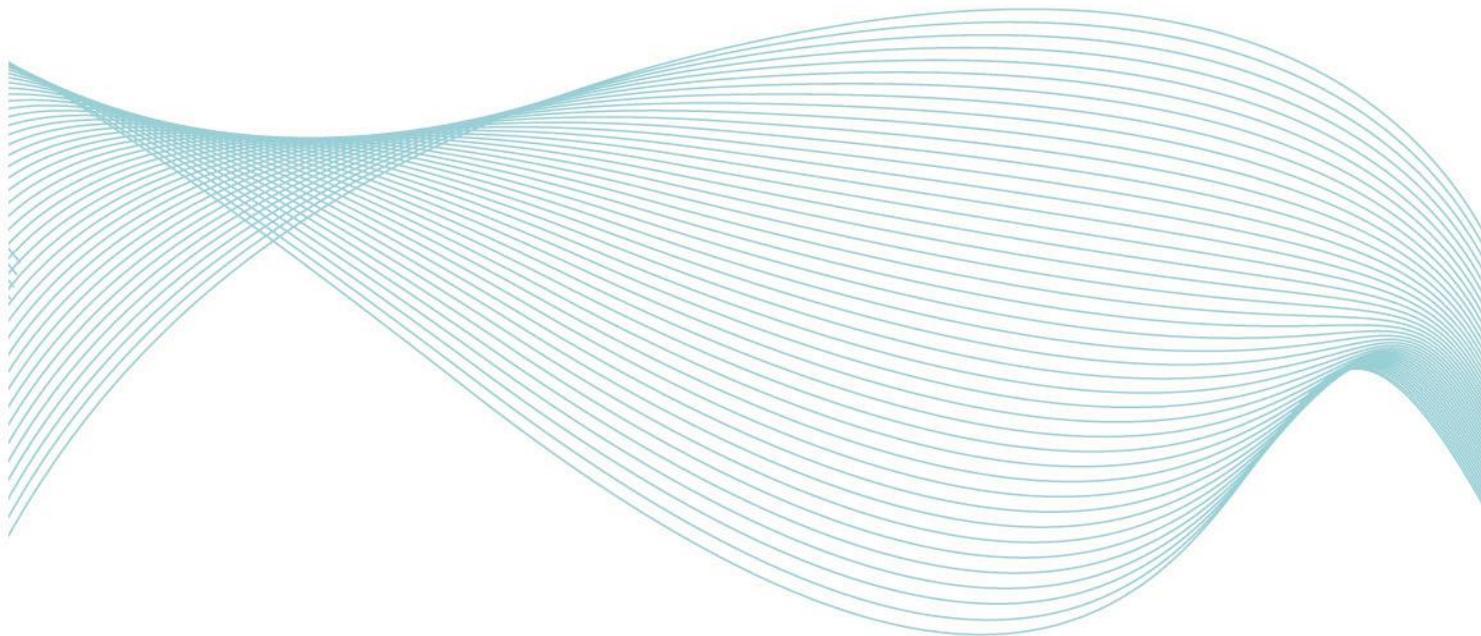
Dr Jeremy Hudson, MBBS, FRACP
Chair of Dermatology, RACGP, Senior Lecturer, James Cook University.
Clinical Director of the North Queensland Skin Centre.

Dr Jeremy Hudson is Clinical Director of the North Queensland Skin Centre, a research-based clinic in Townsville. He has spent most of his career as a rural and remote GP before specializing in skin cancer. He has a strong interest in medical education, improving clinical guidelines and in the early diagnosis of skin cancer using Artificial Intelligence based imaging and confocal microscopy.



Christine Zahren, MAPPSC (ACu), BSN, RN
Business Development Manager, ClinTrial Refer

Christine is the Business Development Manager for ClinTrial Refer. She has a background in nursing with over 25 yrs experience in healthcare. She has worked in various areas of health including aged care, acute care, rehabilitation medicine, dermatology specialist clinics, and surgery. Christine has extensive experience in clinical trials coordination and management. She is passionate about helping advance medical research and ensuring that people have access to medications and new therapies in their development phase.



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