NCI’s Cancer Information Service – Helping Connect Patients to Trials

Lakshmi Grama & Mary Anne Bright - National Cancer Institute - USA
U.S. National Cancer Institute’s Cancer Information Service

- Bilingual, omni-channel Contact Center
- In operation since 1975
- Provides tailored, evidence-based information along the cancer continuum
- Helps people become active participants in their own health care by providing the latest scientific information in understandable language
- Disseminates NCI's key messages and latest cancer information
Connecting Callers With Reliable, Accurate Information

- Cancer Information by Type
- Treatment/Side Effect Management
- Hospital/Clinic/Screening Programs
- Support/Economic Assistance
- Physician/Second Opinion
- Clinical Trials and Clinical Trial Searches
“Ask Us About Clinical Trials”

- Proactively discuss clinical trials as a possible treatment option

- Conduct tailored searches that are sent to inquirers to share with their health care provider

- Proactive chat to support website users who may have trouble with finding trials
Explaining New Types of Trials
Improving Findability of Clinical Trials

- Finding the most appropriate set of trials continues to be a challenge
- Collaborating with NCI’s Clinical Trials Reporting Program to improve the quality of data about trials
  - Structured eligibility criteria
- Potentially help verify and improve future efforts to develop algorithms to match patients to trials
Multi-component approach to improving patient access to trials: the experience in Victoria, Australia

Christie Allan,
Cancer Council Victoria
(Australia)
Recruitment into cancer clinical trials in Victoria is low – between 5% and 6% of all newly diagnosed cancer patients are recruited into a trial.

At any given time, there are between 200 and 300 treatment intervention trials open for cancer patients in Victoria.

Reasons why recruitment is low are multifaceted; patient access and awareness is a contributor.
Multi-component approach:

- Improving patient access to clinical trials
- Building capacity
- Providing consumer friendly information and support
  - Using patient experiences
  - Victorian Cancer Trials Link
  - Cancer Trials Management Scheme
Cancer Trials Management Scheme (CTMS)

- **Pay for data**
  - Stratified funding model that supports the collection of clinical trial activity and recruitment data at Victorian clinical trial sites.
  - $200K distributed annually, awarded over 3 years. Site allocation is predetermined and based on prior activity, resourcing and recruitment.
  - 43 clinical trial sites.
  - 2019.

- **Competitive grants**
  - Awards grants to researchers that propose innovative ways to improve patient access to clinical trials in Victoria.
  - $2.5M distributed between researchers, awarded over 3 years.
  - 4 grants awarded in 2017.
  - 2019.

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A Randomized Controlled Trial of an Additional Funding Intervention to Improve Clinical Trial Enrollment

Catriona Parker, BAppSc(MLS), MAppSc(MedSc); Raymond Snyder, MBBS, MMed, FRACP; Michael Jefford, MBBS, MPH, MHlthServMt, PhD, FRACP; David Dilts, PhD, MBA; Rory Wolfe, BSc, PhD; and Jeremy Millar, BMedSc, MBChB, FRANZCR, FACPMed
Consumer friendly information and support

People searching for a trial on the VCTL

<table>
<thead>
<tr>
<th>Month</th>
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<tr>
<td>May-17</td>
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</tbody>
</table>
Consumer friendly information and support

Learning from consumer experiences

“I didn’t have to be on a clinical trial, I chose to be on a clinical trial.” - Ilka
Find a clinical trial near you.

“Being a part of a clinical trial can be a bit scary because you are going into something that is an experiment. You do rely on the clinical staff to reassure you and be attentive to your needs as a patient.” - Tash
Find a clinical trial near you.

“I chose to go on a clinical trial knowing that there was a whole team collectively working towards the trial.” - Peter
Find a clinical trial near you.

“The opportunity to get a better quality of life, the opportunity of extending your time here with friends and family - I think a lot of people would take that chance to take part in a trial.” - Greg
Find a clinical trial near you.

Consumer friendly information and support

Learning from consumer experiences – Trial Connect

“...Very useful. He was helpful in explaining the sorts of things a trial can entail and how he found certain questions useful to ask.

*It certainly helped me to understand what may be involved in a clinical trial.*

There is no trial suitable trial for me at the moment but it has given me more confidence to investigate in the future.”

“It was good to talk to him. In a strange way I felt good although there was not going to be a trial for me. I spoke to him for an hour. He was keen for me to talk to my Doctor and ask questions... I feel able to ask about future trials.

*He was a good listener.*

Trial Connect
One to one support from someone who's had a similar experience.

More information
Conclusions:

Sector engagement in the Victorian Cancer Trials Link and Cancer Trials Management Scheme means:

- We are able to report complete cancer clinical trial activity in Victoria.
- Greater opportunities to build capacity of the sector and increase patient access to clinical trials.

Learning from consumer experiences is essential to improve patient access to clinical trials.

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Or visit:
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Communicating About Clinical Trials

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Talking about cancer trials with young people

- Widespread reports that participation of young people with bone cancer (sarcoma) in clinical trials is low although open trials are available; the reasons for this aren’t well understood
- We investigated factors that influence trial participation of young people (aged 15 -24) with bone cancer (Pearce et al., 2016; Lavender et al., unpublished)
- In-depth interviews were conducted with 21 young people and 18 health professionals (HPs) at a teenage and young adult (TYA) cancer centre, which was also a regional sarcoma centre
- A combined ‘analytical framework’ was developed from thematic analysis of all interview transcripts (Pearce et al., 2016) and additional distinct emergent themes identified from HP interviews (Lavender et al., unpublished)
Combined analytical framework

- What the TYAs and HPs said about bone cancer clinical trial participation had ‘high-level agreement’

We identified:
- **Critical time points** where arguably more support is needed

- **Influencing factors** on weighing up benefits (enablers) and burdens (barriers) of clinical trial participation
Emergent themes from health professional interviews: Patient-professional trust

- Professional expertise and the development of specialist knowledge and skills
- Strategies used to develop trusting relationships

We aligned our findings about how health professionals communicate about clinical trials with young people with four characteristics of patient-physician trust (Hillen et al., 2011)
What we learned...

- The design of clinical trials should consider the acceptability of the trial.
- Additional care and support is needed at critical time points.
- Addressing influencing factors should improve participation in clinical trials.
- Using a family-inclusive approach and facilitating peer-support helps the decision-making of young people about trial participation.
- Trusting patient-professional relationships are central to communicating effectively about clinical trial participation.
- Strategies used by health professionals to communicate can inform training and enable the development of specialist expertise within local contexts.
- Effective communication increases team-work and reduces confusion across care settings.
- Nurses are an important part of the team for ensuring continuity in communication, information sharing and provision of care.
- There is scope to transfer our findings to other contexts of clinical trial recruitment: Effective communication is central to trial success.
References


• Lavender, V., F. Gibson, A. Brownsdon, L. Fern, J. Whelan, and S. Pearce, Health professional perceptions of communicating with young people about bone cancer clinical trial participation, Supportive Care in Cancer (2018) doi: 10.1007/s00520-018-4337-4

• Pearce, S., A. Brownsdon, L. Fern, F. Gibson, J. Whelan, V. Lavender, The perceptions of teenagers, young adults and professionals in the participation of bone cancer clinical trials, European Journal of Cancer Care (2016) doi. 10.1111/ecc.12476
Engaging clinical nurse specialists and research nurses in enhancing patient access to clinical trials.

Anne Croudass, Cancer Research UK (United Kingdom)
Context

• Recruitment to clinical trials remains an NHS priority

• As a major funder of cancer research, CR UK recognise that progress can only be made if patients consent to take part in trials

• Research nurses are instrumental in recruiting patients to trials, but patients form relationships with other health professionals who can influence their decision making
Why the round table?

Cancer care is truly multi-disciplinary and all members of the MDT should be trial aware:

- To improve patient experience
- To increase trial awareness
- To improve recruitment
Process

Facilitated discussion to identify strategies to improve collaboration for the benefit of patient care.

Attendees:

- five CNSs,
- four CRNs
- one joint CNS/advanced clinical trials practitioner
- senior cancer information nurse
Themes

- Communication
- Information
- Training
- Shared care
- Workload pressures
Reflections

• Useful opportunity to improve understanding of priorities for each role and an appreciation that both want what is best for patients.
• Some excellent practice locally.
• Communication was recognized as key.
• We are all nurses who want the best for our patients. We need to put them at the heart of what we do rather than focusing on what we think our different roles are.
What next?

Consensus was reached that adopting a shared ownership of talking to patients about clinical trials was needed, so we are planning to investigate how best to support that.