Patient Driven Data to Drive Change

Moderator: Jeff Dunn, The University of Southern Queensland (Australia)

Presentations:

Pru Etcheverry, Leukaemia & Blood Cancer New Zealand (New Zealand)

Richard Vines, Rare Cancers Australia (Australia)

This session will highlight how patient driven data can increase disease awareness, influence health policy outcomes and generate change. Number (code): SP15
Patient Driven Data

Using data to drive change

“Without data you are just another person with an opinion”

[W. Edwards Deming]

Richard Vines – CEO, Rare Cancers Australia
Data Fundamentals

• Know your destination – what am I trying to demonstrate?
• Not an academic pursuit – not looking for a PhD!
• Data can be used for many purposes:
  • Attention Getter – awareness raising
  • Proof of the need for change
  • Support policy recommendations
  • Much more
• Data Presentation is as Important as Data Collection
CASE STUDY: Rare Cancers Australia – Just a little more time
Reports 2014 & 2016

The Problem:

• Health system focused on doing “The Most for the Most”
• No public or government awareness or understanding of rare cancers
• No reliable definition of rare cancers in use in Australia.
• **No readily available data to support our case**

The Consequence:

• Minimal Treatment Options,
• Late diagnosis, Low survival
• No research, no clinical trials
Aim:
To represent cancers other than Breast, Lung, Melanoma, Bowel, Prostate & Non-Hodgkins “Not Common” rather than rare!

2 Definitions
• Rare cancers are those with an incidence of less than 6 per 100,000
• Less common cancers are those with an incidence of between 6 and 12 per 100,000 inclusive
CASE STUDY: Rare Cancers Australia – Just a little more time
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Available Data

- All Cancers
- All Common Cancers
- Some rare or less common cancers as examples.

- The **difference** was our data source (All less Common)
  - Incidence
  - Mortality
  - Research Funding
  - Treatment Funding (Public Funding through the PBS)
“Just a little more time”
Report, March 2014
Rare and Less Common Cancers (RLC)

Objective
“To present a summary of the current state of RLC Cancers in Australia that would kick-start the search for improved research, diagnosis and treatment”
What are Rare and Less Common Cancers?

A ‘rare cancer’ is defined as a cancer type found in less than 6 per 100,000 Australians per year.

And ‘less common’ cancers found in between 6 & 12 per 100,000 Australians per year.

Definitions
What is the Diagnosis?

Every year, 42,000 Australians are diagnosed with a rare or less common (RLC) cancer. Overall, an estimated 124,910 cases of cancer will be diagnosed in Australia each year. This means rare cancers make up about 30% of all diagnoses but account for 50% of cancer deaths.

Incidence & Mortality
Comparisons

The rate of RLC diagnosis and mortality is currently TWICE THAT OF THE POPULATION GROWTH.
**Projections**

22,000 Australians will die due to an RLC every year accounting for 50% of cancer deaths.

**Mortality Rates**

Common vs RLC Mortality Increase since 1990 compared to Australian population increase:

- Common Cancer % Increase Mortality
- RLC Cancers % Increase Mortality
- Population % Increase

Rare Cancers Australia
A voice for less common cancers.
Research and Treatment

RLC Cancers receive 13.5% of research funding compared to their contribution of 50% of all cancer deaths. Considering PBS Funding, RLC Cancers receive 12.6%.

1 in 2 Deaths
What NEEDS TO HAPPEN?

Innovative research that leads to earlier detection and better treatment

Increased availability of PBS funded treatments and equal access to care and treatment regardless of cancer type

Without concerted action in research, diagnostics and treatment, Australia could be confronting over 30,000 deaths from RLC Cancers by 2020

and over 40,000 by 2030

Call to Action
Seeing The World Differently Through Data

Australian Data
Over 800 Children lose their mother to breast cancer every year.
Over 3000 Children lose their mother to cancer every year

How do we know?
Mortality Data by age combined with Fertility Data by Age.

Estimates are OK!
Any Questions?

THANK YOU!
Patient Driven Data to Drive Change

Pru Etcheverry, Lymphoma Coalition
Patient Driven Data to Drive Change
Patient Experience Data

Without intentionally including patients and their experiences and data we are unintentionally excluding them.
Patient Experience Data

The better informed patient does better

The better informed system does better for patients
Lymphoma Coalition
Global Network of Patient Groups

• Since 2002 – incorporated in 2010
• 75 member organisations – 50 countries
• Global Board of Directors
  • + access to 70 around the world
• Patient leaders in all blood cancers
• Building strength globally, and acting with strength locally
• Gathering and disseminating information on all lymphomas including CLL
• 650,000+ database
• Creating a level playing field of information

www.lymphomacoalition.org
A Level Playing Field of Information
Creating a Robust Bank Of High-Value Resources

LC Data Collection

Patient Survey
(6,631 respondents ‘18)
(4,000 respondents ‘16)
Every 2 years since 2008

Resource Library
2,500 pieces of information
& Best Practice Library

Global Database
(by subtype & country for therapies & clinical trials)
2016 LC Global Patient Survey on Lymphomas & CLL

4,154 respondents globally
14 countries with 100+ responses

Age Range
- 18-29 (9%)
- 30-45 (22%)
- 46-65 (42%)
- 65+ (27%)
Know Your Subtype

When patients with lymphoma were asked about their subtype...

1 in 4 could not identify their lymphoma subtype

2 in 5 did not understand the characteristics of their lymphoma subtype

#knowyourssubtype

SOURCE: 2016 GLOBAL PATIENT SURVEY ON LYMPHOMAS © LYMPHOMA COALITION
Know Your Subtype

NHL is **not** a disease. Patients need to know their **subtype**.

Let’s make the patient experience smoother.
Know Your Subtype

Long term follow-up ibrutinib and rituximab combination in patients with R/R MCL
Sep 12, 2018

Ibrutinib did not meet the primary efficacy endpoint in patients with R/R...
Sep 5, 2018

Mayo Clinic Lymphoma eTumor Board | Spontaneous regression in a DLBCL,...
Aug 24, 2018
2018 LC Global Patient Survey on Lymphomas & CLL

6,631 respondents globally
14 countries with 100+ responses

48% male, 52% female

71% of respondent over age 40
The Knowledge Age: ‘Better’ Outcomes for ‘Informed’ Patients?

Natalie Dren, MSc
LYMPHOMA COALITION 2017

Lymphoma Coalition Definition of Informed Patient

‘Any patient that is informed on their subtype, has a very good understanding of the diagnosis, and has a say in their course of care (treatment and psycho-social). The patient is engaged with a supportive healthcare delivery system, where they are included in information discussions, and are provided with direction on the best information and support for their subtype. The patient is respected as a person and their questions are listened to, heard, and the response elicits a sense of trust—allowing patients to gain confidence in maintaining an active role throughout their patient experience.’
Standards of Excellence Program

The patient survey revealed patients need additional support beyond what they are receiving from health care professionals.

While patient organisations can often fill the gap, in most countries patients are not (often enough) being referred.
Therapy Information & Availability

- By country
- By subtype
- By line of therapy
Initiative for Innovative Approach to Improving Access to New Medicines in Serbia

4 non profits

Hired an expert on pharmacoeconomics

Pragmatic Value Assessment (PVA) System

Scoring system:
• Cost effectiveness
• Clinical benefit
• Social Issues
• Ethical Aspects

Low number of therapies approved in Serbia

Minister of Health
✓ Listed 23 more therapies
✓ Patient representatives are now included in decision-making bodies at the Ministry of Health and the HIF

A panel discussion entitled “How close are we to having up-to-date healthcare in Serbia?”

“Modernising the Serbian Health System” was published in The Economist

Media

SERBIA – No Defined HTA System
Canada – Drug approval in CLL

8 July 2016 submitted for approval

22 July 2016 patient group submission using patient survey data

1 December 2016 drug not recommended for funding

Pharma withdrew submission

10 July 2017 submitted for approval

24 July 2017 patient group submission using updated survey data

30 November 2017 drug not recommended for funding

14 December 2017 patient group feedback

2 March 2018 final recommendation from regulatory body conditional reimbursement if an improvement in cost until more robust clinical data are made available for a future assessment
Canada – Drug approval in CLL

Submission from Canada have been used globally by other organisations to get approval in their countries
Summary

- Don’t lose sight of the power of individual
- Empowering and educating patients is vital
- Integrating patient experience data is essential for improving outcomes
- The better informed patient does better
- The better informed system does better for patients
- Patients need to be partners in care not just recipients of care
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