Patient Public Involvement in MS Research

Alison Thomson
Alison Thomson has received funding from Roche, Biogen, Novartis and Sanofi Genzyme along with honorariums from Merck and Sanofi Genzyme.
What is public involvement in research?
What is public involvement in research?

INVOLVE defines public involvement in research as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them. This includes, for example, working with research funders to prioritise research, offering advice as members of a project steering group, commenting on and developing research materials, undertaking interviews with research participants.
Non-Researchers?

- Understand current research
- Disseminate current research
- Communicate experience
- Two-way communication.
- Greater communication between patients and researchers.
  - Mutual benefit
- How can non-researchers' knowledge be valued and rewarded. Recognition!
  - Recognising that other non-researchers are the experts, too.
- Sharing experiences with others in similar situations
- Non-professional views. Input other perspectives.
Researchers

- Keeping Patients Involved
- Recruiting Patients
- Running Focus Groups
- Moving beyond one-off groups
- Setting Expectations
- Meaningful Involvement

Mutually Beneficial

What can patients contribute? How?

Integrating PPI/PE into Basic Science Research

What is success? For whom? Specific?
Barts MS Advisory Group
Invitation from
Professor Gavin Giovannoni, Barts and The London School of Medicine and Dentistry.

The 6th MS Research Day

Saturday 23rd March 2013, 9am-3pm
Registration 9.30am
Lunch 12.15-1.15pm
Church House Conference Centre
Dean's Yard
Westminster
London SW1P 3AZ

Entrance via Great Smith Street
National Gallery for 72 steps up the District Line.
RSVP an attached card or via e-mail to:
www.mresearchday2013.eventbrite.co.uk

Register
Clinical Bank
Society

BartsMS Research
Day

Presentation slides
We are providing a few paper copies of the presentation slides per table for people who would like to take notes.
Before you start fingolimod you need to consider how you may transition to a new treatment

Disease reactivation is a problem with migration inhibition drugs.

Wednesday, 5 September 2018

Has your neurologist discussed HPV vaccination with you?

What to advise MSers about the HPV vaccine?
Pageviews today 2,069
Pageviews yesterday 3,304
Pageviews last month 91,728
Pageviews all time history 11,845,624
Followers 266

Manage tracking your own pageviews

Posts

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Traffic Sources

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Audience
How to start a blog
Alison Thomson, Dominika Raciborska, David Baker, Gavin Giovannoni

ABSTRACT
Blogs that address issues of health and medical education run by clinical and research teams can have a profound impact on how patients access and navigate health information. Regularly updated websites are useful tools to facilitate two-way communication with a range of different audiences, from patients to the general public. They provide benefits of supporting patients to learn and self-manage their health, and to educate colleagues and disseminate research. This article describes how to set up a blog, pointing out some simple style and formatting considerations, usable methods and appropriate conduct for healthcare professionals to engage with patients online.

WHAT IS A BLOG?
A blog (web log) is a regularly updated website or web page, typically run by an individual or small group, that is written in an informal or conversational style. It can help to improve engagement and involvement among, and within, different groups of people, such as patients, researchers, clinicians and the general public. The internet and social media have had a profound impact on how patients access and navigate health information. It is up to professionals to join them in this space and to start a conversation. The emphasis is on conversation; it is a two-way process that requires listening and the time, effort and skills to respond in a way that ensures the reader and the blogger are equal partners. Blogging is more than a soapbox.

WHY START A BLOG?
Setting up a blog is a simple way to get information out to patients in a timely manner and to educate and engage them in meaningful discussions about their health. Furthermore, technology allows health information to be communicated in interactive and engaging formats using image, video and sound. We set up the Barns MS (multiple sclerosis) Research blog (www.ms-rex.org) in 2009, as clinicians found themselves waging a large amount of clinical time repeatedly debunking a pseudoscience theory and a binge treatment for MS. Writing a series of blog posts explaining why this therapy was incorrect meant that patients could be referred to the posts providing more in-depth information, saving valuable clinical time for more important issues. This article will share some of what we have learnt over many years of running a blog, and hopefully encourage others to set up and engage with patients online in a professional capacity.

AUDIENCE
The most important aspect of blogging is having a clear idea of who your blog is for. This will determine how your blog functions, what you will write about and how you will write it. A blog for a patient audience should be very different than one for a professional, specialist or research audience. The Barns MS Research blog has far wider audience than was initially intended and ranges from patients, researchers, funders, pharmaceutical executives and clinicians. In a recent survey of 266 of our blog readers, 152 people use it to self-manage their condition, 12 healthcare professionals use it to discuss topics of MS research or care with colleagues, while 8 researchers said it informs their opinion of other research.

"Your blog is invaluable. I focus on the most promising research and treatment, clinical needle in a haystack."

"Provides a greater understanding of MS. Evidence that research is happening."

"Encouraged me to keep on living when I was feeling suicidal. You did great work."

Clinic Speak: resources that use clinical, design and technical expertise to improve the experience of monitoring MS. For people with MS, their families and their medical teams.
27,000 users

3,800 users
REF impact case study

20,000 users

11,000 english
3,000 brazilian portuguese

2,000 english
3,000 brazilian portuguese

Launching soon
What are the risks of Tysabri?

With most drugs, there are risks linked to the long term use of Tysabri. The main risk is a potentially fatal brain infection, called progressive multifocal leukoencephalopathy (PML).

What's your risk of developing PML?

1 in 286 people develop PML

PML is caused by the JC virus, a common virus completely unrelated to MS. Almost half of the general UK population are infected with the JC virus in childhood and adolescence.

It’s impossible to predict if you'll get PML, but there are a number of factors that can increase your risk.
The Lumbar Puncture Procedure

What to expect before, during and after your Lumbar Puncture.
Alemtuzumab (Lemtrada) safety advice: Listeriosis prevention

Preventing Listeriosis (an infection caused by Listeria bacteri) before, during and after treatment.

Who is at risk?
- People who are immuno-suppressed
- People with diabetes
- People with chronic liver disease
- People with chronic infections
- People with chronic inflammatory diseases
- People with chronic respiratory disease
- People on long-term antibiotic treatment
- People on long-term immunosuppressant treatment

What to avoid?
- Fruits
- Vegetables
- Raw or undercooked meats
- Hot dogs
- Soft cheeses
- Seafood
- Deli meats

What’s safe to eat?
- Cooked vegetables
- Cooked meats
- Cooked seafood
- Cooked deli meats

Weekly Checklist:
- Fridge temperature is less than 5°C
- Food in the fridge is within its use-by date
- Open food in the fridge is less than one day old
BartsMS

ms-res.org
@bartsMSblog
@somehow_related