

Advocacy in action... and in austerity

Sir Nick Partridge

Terrence Higgins Trust, UK

May 2013

MS and HIV in the UK

Many similarities, many differences:

- 100,000 people with MS – the same as HIV
- Average age of diagnosis – 35 for both conditions
- Life expectancy reduced by about 5 years
- Dramatic improvements in drug treatment for HIV over past 15 years – on their way for MS?
- HIV is infectious, MS is not
- HIV impacts specific communities and is focused in urban areas

A short history of HIV and THT

- Terry died in July 1982, THT set up in November that year
- Profound shock and fear of new, deadly, sexually spread virus
- Taboos and fears – sex, sexuality, drug use, contagion and dying young
- Challenge to Dr / patient relationship, medical research orthodoxy, provision of social care, rise of the expert patient
- Speed of drug development – protease moment in 1996 with 70% fall in deaths in 18 months
- HIV changed from a death sentence to a long term, manageable condition





Find out more

- ▶ What is public involvement in research?
- ▶ **Public involvement in research**
- ▶ Interested in getting involved?
- ▶ Information for researchers
- ▶ Research commissioning
- ▶ Frequently asked questions
- ▶ User controlled research

Public involvement in research

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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.

View a video of our members and Nick Partridge, our previous Chair, talking about what public involvement in research means to them.





The James Lind Alliance Guidebook

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▶ Introduction

▼ How To

▼ [How to establish a Priority Setting Partnership](#)

▼ [Overview of Priority Setting Partnerships](#)

- Who's who in the Priority Setting Partnership?
- ▶ Setting up the steering group
- ▶ Identifying partners
- ▶ Managing the partnership
- ▶ How to identify treatment uncertainties
- ▶ How to prioritise uncertainties
- ▶ How to evaluate
- ▶ How to take priorities to research funders

Overview of Priority Setting Partnerships

Priority Setting Partnerships bring patients and clinicians together to work through the JLA process. The aim of a Priority Setting Partnership is to identify patients' and clinicians' shared priorities for research into the treatment of specific health problems.

The JLA's current portfolio of Priority Setting Partnerships can be viewed by clicking [here](#).

Priority Setting Partnerships' objectives are to:

- bring patients and clinicians together to identify uncertainties about the effects of treatments
- agree by consensus a prioritised 'top 10' list of those uncertainties, for research
- publicise the methods and results of the Priority Setting Partnership
- draw the results to the attention of research funders, independently of the JLA

Advocates of the following groups are invited to take part in a Priority Setting Partnership:

- people who have or have had the health problem in question
- carers of those affected
- medical doctors, nurses and allied health professionals with experience of caring for people with the health problem



MS news & research

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A new way of prioritising MS research

Posted on 15 Apr 2013 at 5:16PM by Emma Gray

Our fundamental aim is to develop a strong research agenda that results in life changing benefits for people affected by MS.



Often researchers and funders play the dominant role in the development of research strategies, and the priorities and voices of people affected by health conditions struggle to be heard.

Here Mital Patel from the Research Team explains how you can get involved in our [project to gather and prioritise research questions](#) that are most important to people affected by MS and healthcare professionals.

Putting people affected by MS at the heart of research

At the MS Society we're always working on ways to make our research programme inclusive and reflective of the needs of people affected by MS. That's why we've embarked on this project guided by the [James Lind Alliance \(JLA\)](#). The JLA have an internationally recognised method of helping to prioritise research questions from people with health conditions, carers and healthcare professionals.

This project is a new way of canvassing the views of a wide range of people who would not normally be involved in strategic activities like setting research priorities. By the end of the project we'll have developed a top 10 list of unanswered research questions shared by people affected by MS and healthcare professionals. This top 10 isn't just for the MS Society, it's for the whole MS community, and it will hopefully go on to influence the decisions of many research funders.

Get involved: Vote today!

You can now [vote for research questions](#) most important to you - just follow the on screen instructions.



Often researchers and funders play the dominant role in the development of research strategies, and the priorities and voices of people affected by health conditions struggle to be heard.



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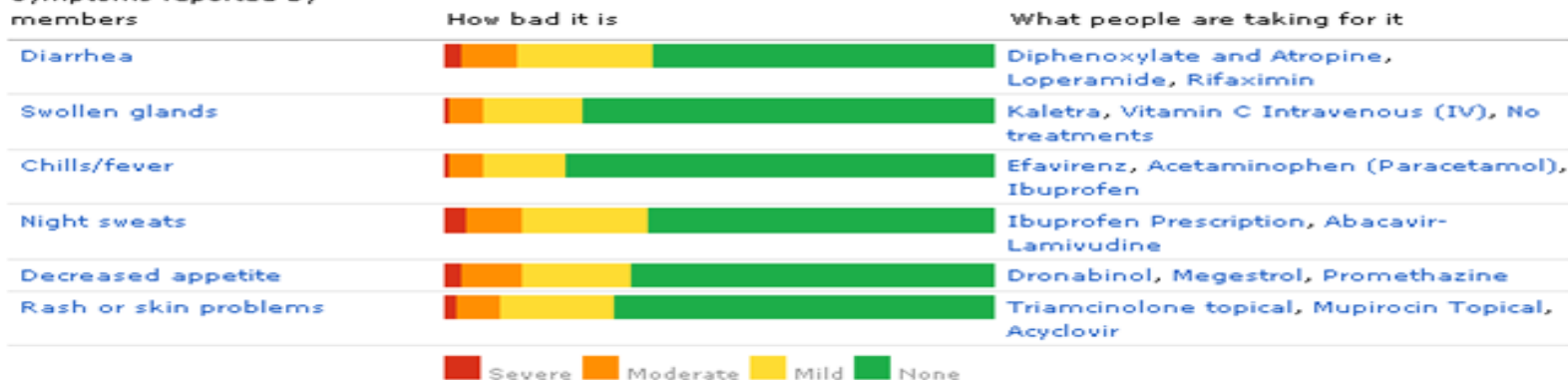
Your rating: None Average: 5 (1 vote)

Patients Like Me - HIV



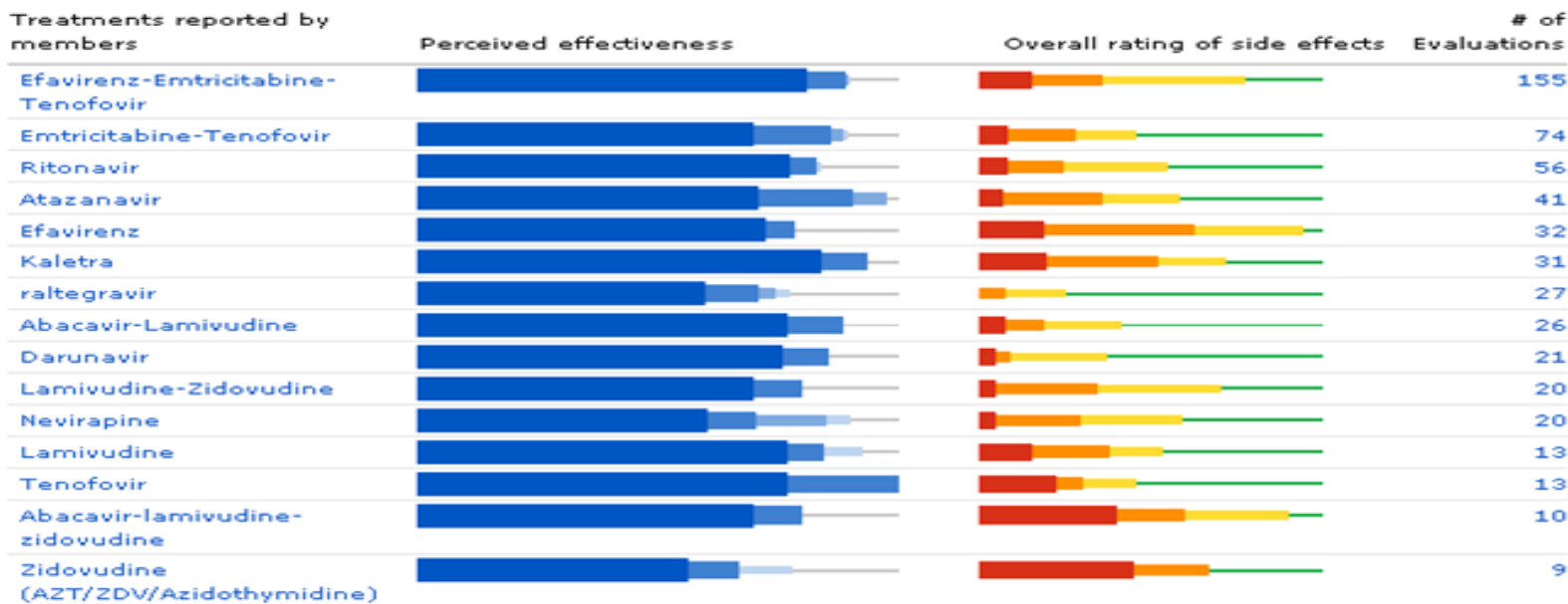
What is it like to have HIV?

Symptoms reported by members



What do patients take to treat HIV and its symptoms?

Treatments reported by members



These charts show data from HIV patients' latest treatment evaluations

Patients Like Me - MS

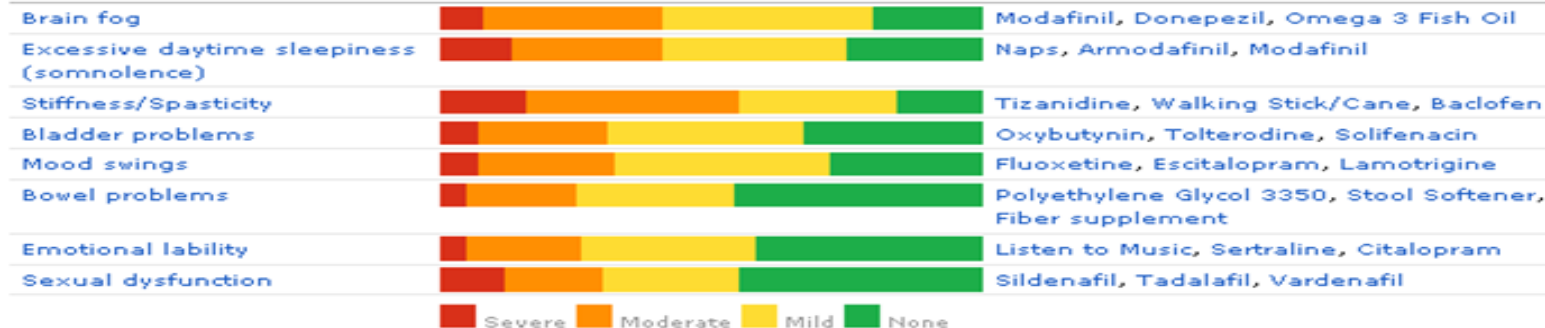


What is it like to have MS?

Symptoms reported by members

How bad it is

What people are taking for it



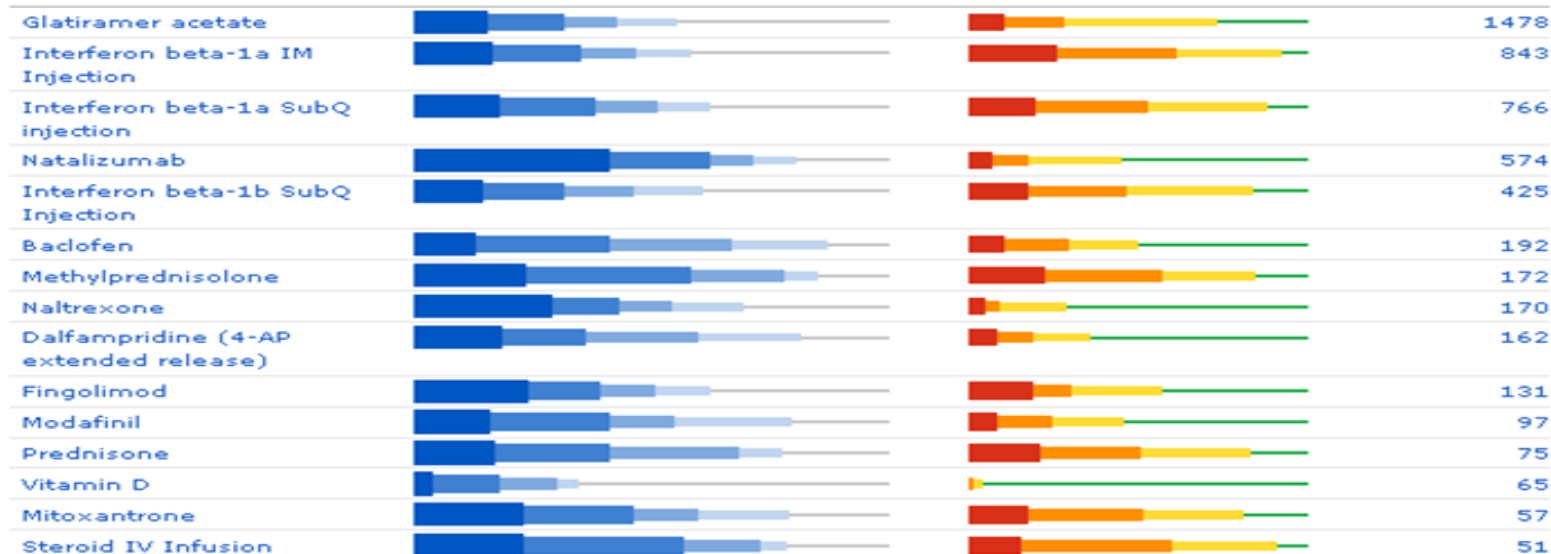
What do patients take to treat MS and its symptoms?

Treatments reported by members

Perceived effectiveness

Overall rating of side effects

of Evaluations



These charts show data from MS patients' latest treatment evaluations

My medication and reminders

My CD4 count and viral load

Ask a health trainer

My personal notes

My appointments

My favourites

My life check

Share my story

Community forums

My account details

My CD4 count and viral load

Record your CD4 and viral load results as you get them and track them here over time.

Your CD4 count gives a rough indication of the strength of your immune system. Your viral load shows how active HIV is in your body.

For more information see [What's happening inside me?](#)

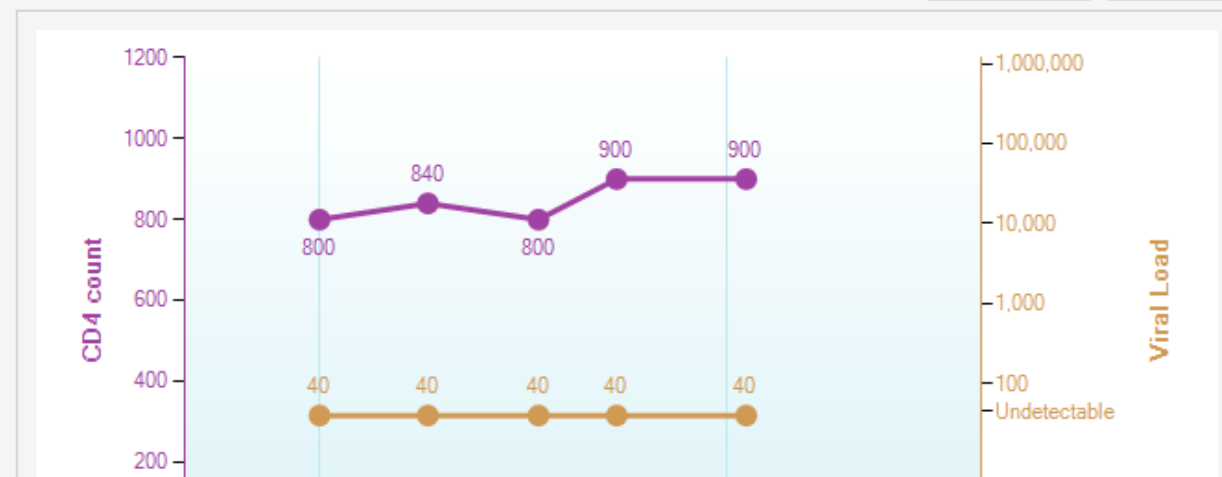
Levels

My latest results

- > 18/01/11 900 CD4 count
- > 18/01/11 40 Viral load

Year to date

All results



Email:

Password:

[Forgot Details?](#)



*Help Make Sense of MS

The MS Register is a ground-breaking study designed to increase our understanding of living with MS in the UK. [Join the study](#) by completing a series of simple questionnaires.

Email*

Password*

Confirm Password*

*Required

Join the Study

If you are over the age of 18 and living in the UK, with a confirmed diagnosis of Multiple Sclerosis made by a consultant neurologist, you are eligible to take part in this ground breaking study.

Once you've completed the registration form, you'll find a simple multiple choice questionnaire to complete; this should only take around 10 minutes. We then ask that you return regularly to repeat the simple process

*10280 people have joined the study so far.

Care, support and employment

- **UK welfare reforms** have the biggest potential impact – intended to save £8 billion and reduce the number of claimants by around 30%
- **Disability Benefits Consortium** - national coalition of over 50 organisations working towards a fair benefits system.
- **Hardest Hit** - the public-facing campaign against the disproportionate impact on disabled people of benefits and services cuts.
- **Worklife** - a web project to support people with chronic fluctuating health conditions in employment.
- **Care & Support Alliance** - calling for urgent reform to tackle the social care funding crisis.

Lessons from HIV

- Mobilise personal, political, social, commercial, media forces – gather momentum
- Maximise the voice of people with MS through campaigning web platforms
- Explore the exciting new possibilities for collecting evidence and sharing it
- Have an eye on the long-term, but plan short-term – flexibility is key
- United we stand – the importance of allies
- “Never, never, never give up” Winston Churchill

Useful links

Terrence Higgins Trust – www.tht.org.uk

MS Society UK – www.mssociety.org.uk

INVOLVE – www.invo.org.uk

James Lind Alliance - www.lindalliance.org

Patients Like Me - www.patientslikeme.com