Curriculum Vitae

Personal information

Russell Wheeler

Work experience

1. Voluntary role: EURORDIS
   - Start date: 11/2012
   - End date: Current
   - Position: Volunteer Patient Advocate
   - Activities: EURORDIS sponsored delegate to ISPOR 2012-2017 representing patients on the steering committee for the special interest group for patient engagement in research. Presentations at ISPOR conferences and publications including ISPOR's much cited publication defining patient engagement.
   - Member of DITA task force 2013-present, alternate EURORDIS member of PCWP (EMA) 2019-present, member of Network Advisory Group on Raw Data (EMA) 09/2019-present, member of ACT-EU MSP Advisory Group 03/2024-present
   - Member of HTA task force 2019-present
   - Member of ERN Steering committee 2017-2022
   - Country: France

2. Voluntary role: The Leber's Hereditary Optic Neuropathy Society
   - Start date: 05/2014
   - End date: Current
   - Position: Patient Advocate and Trustee
   - Activities: Retired from employment in 2012 and engaged as a patient advocate on behalf of LHON patients, founding LHON Society in 2014, representing patients in regulatory and reimbursement processes in UK and Europe. Complimentary role with Ouvrir les Yeux in France (French equivalent of LHON Society).
   - Country: United Kingdom
3. Voluntary role: ERN-EYE
   - Start date: 04/2017
   - End date: Current
   - Position: Patient Advocate
   - Activities: ePAG member and co-chair of ePAG and board member of ERN-EYE 04/2017-09/2022. Patient supporting partner from 09/2022 to date. Patient representative on research, registries and neuro-ophthalmology working groups. Member of various groups delivering clinical consensus statements and co-author on several papers relating to rare eye disease and issues associated with their treatment and regulation. Educational outreach and training provision on matters relating to rare eye disease, patient engagement and regulatory/reimbursement issues.
   - Country: France

4. Employer: Winchester Strategic Consulting Ltd
   - Start date: 01/2005
   - End date: 05/2012
   - Position: Director
   - Activities: Provision of financial and strategic advisory services in the field of mergers, acquisitions and joint ventures. Development of knowledge management system for EU institutions and EU evaluation of financial services business on behalf of DG REGIO
   - Country: United Kingdom

5. Employer: Hampshire County Council
   - Start date: 07/2002
   - End date: 01/2005
   - Position: Business Manager
   - Activities: Managed self_contained business unit with 100 staff providing IT support services to Hampshire schools
   - Country: United Kingdom

6. Employer: The Savola Group
   - Start date: 11/1997
   - End date: 01/2002
   - Position: Director, Corporate Development
   - Activities: Managed department for developing group strategy and oversaw several strategic acquisitions and divestments for this, the largest non_petrochemical conglomerate in the Middle East.
   - Country: Saudi Arabia

7. Employer: The Sumitomo Bank
   - Start date: 04/1984
   - End date: 12/1996
   - Position: Assistant General Manager
   - Activities: Established and led European investment banking department responsible for advice on M&A & JVs throughout Europe for both European and Asian clients including pharma sector clients
   - Country: United Kingdom

Education and training

1. Subject: EUPATI
    - Start date: 09/2014
    - End date: 12/s2015
    - Qualification: Patient Expert Program
    - Organisation: IMI funded project for development of patient experts throughout the EU, composed of online learning and face to face sessions.
    - Country: Belgium
2. Subject: EURORDIS Summer School (June 2012) and Winter School (March 2018)
3. Subject: UMIST, Manchester (University of Manchester)
    - Start date: 091973
    - End date: 071976
    - Qualification: BSc Management Sciences
    - Organisation: Marketing, International Business, Finance
    - Country: United Kingdom

Additional information

Publications

Research Priorities for Mitochondrial Disorders: Current Landscape and Patient and Professional Views

May 2022
Journal of Inherited Metabolic Disease 45(10)

DOI:
10.1002/jimd.12521

The top ten research priorities for rare mitochondrial diseases: results of a patient/health professional priority setting partnership

January 2021
Acta Ophthalmologica 99(S265)

DOI:
10.1111/j.1755-3768.2020.0024

Defining Patient Engagement in Research: Results of a Systematic Review and Analysis: Report of the ISPOR Patient-Centered Special Interest Group

April 2020
Value in Health 23(6)

DOI:
10.1016/j.jval.2020.01.019

Prostate cancer screening with prostate-specific antigen (PSA) test: A clinical practice guideline

September 2018
The BMJ 362:k3581

DOI:
10.1136/bmj.k3581

An ontological foundation for ocular phenotypes and rare eye diseases

January 2019
Orphanet Journal of Rare Diseases 14

Labs: ERN-EYE
Copenhagen Optic Nerve Research Center

Case for a new corticosteroid treatment trial in optic neuritis: Review of updated evidence

November 2019
Journal of Neurology, Neurosurgery, and Psychiatry 91(1):jnnp-2019-321653

DOI:
10.1136/jnnp-2019-321653

What Do We Mean by Patient Engagement? A Qualitative Content Analysis of Current Definitions

April 2018
Value in Health 21:S89

DOI:
10.1016/j.jval.2018.04.597

Attributes Defining Patient Engagement And Centeredness In Health Care Research And Practice: A Framework Developed By The Ispor Patient-Centered Special Interest Group

October 2016
Value in Health 19(7):A487

DOI:
10.1016/j.jval.2016.09.812

Projects

Involvement in various ERN-EYE projects including:

- Clinical Consensus Statement for Low Vision
- Clinical Consensus Statement for MOGAD
- Clinical Consensus Statement for LHON
- Joint Academic/Clinician/Industry working group on regulatory challenges for Rare Eye Diseases (REDs)

Involvement in EMA committees including:

- PCWP Alternate member for EURORDIS
- Member of drafting group for input into ICH E6 revision
- Member of Advisory Group on Raw Data
- Member of MSP Advisory Group for ACT-EU

EURORDIS Activities including:

- Member of DITA Task Force
- Member of HTA Task Force

Memberships

Other Relevant Information

I am a patient representative primarily engaged in two main areas, although the are closely connected:

Patient involvement in research

I passionately believe that this is not a "nice to have" but a "must have" element of research; not for reasons of fairness or equity, important though those are, but for reasons of efficiency. Patient input into research at all stages is in the overwhelming majority of cases likely to be better quality research. And in those few cases where it is not, that is simply because it has not been done properly. Finding enough patients qualified to fulfil this need is a real challenge, however, and patient education is sadly lacking.

Patient involvement in regulatory and reimbursement decisions

The same holds true in regulatory and reimbursement decision-making, where decisions taken without proper and effective patient input are in danger of being flawed. Unfortunately many patient organisations fail to recognise and work to improve this situation, except when it is too late and there is an inevitable rush to condemn decision makers for decisions taken that are considered to be against the patient interest. This often turns out to be counter-productive and is an inefficient use of resource (for patients and for authorities). Far better to invest in understanding the regulatory and reimbursement processes and engage fully in order to ensure a fair and thorough assessment is delivered than to complain about it afterwards. Where the evidence base is weak patients should work with sponsors to seek ways to strengthen it and should be demanding of such proof themselves, not just because it is required by regulators.