

On 8/Mar/2011 started on a



- **Multicentre, Double-blind, Randomized, Parallel-group, Monotherapy, Active-control Study to Determine the Efficacy and Safety of XXXXX versus YYYYYY in Patients with Relapsing-Remitting Multiple Sclerosis”.**
- **144 weeks with monthly visits to center (~80km).**
- **Found out about the trial through my neurologist.**
- **Felt like a Study Number- not a person.**
- **Wasn't aware of IPPOSI or www.clinicaltrials.ie**
- **PATIENT INFORMATION SHEET was 21 pages long.**
- **My first child had been born in the Netherlands in 2004. I had access to e-health then.**

Wanted To Do More!



Patients have a key role in all aspects of health-related research



Competent authorities



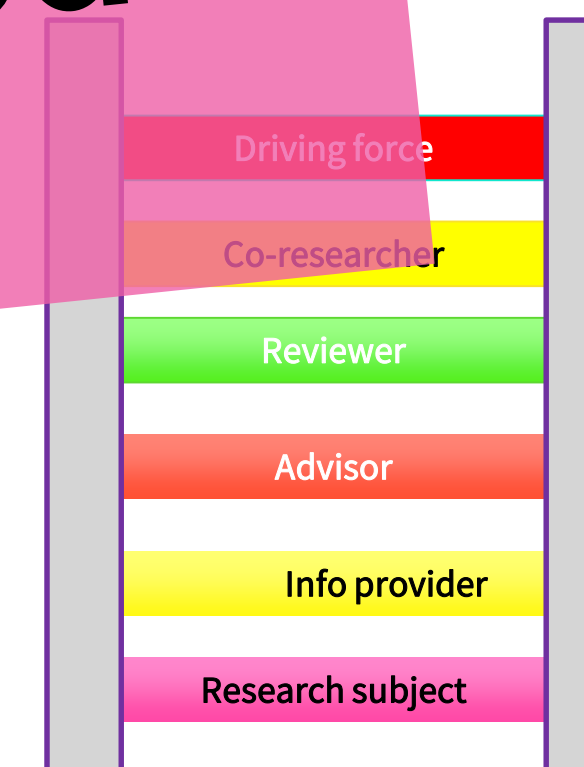
Are there enough patient advocates to be involved where needed?



Research Ethics Committees

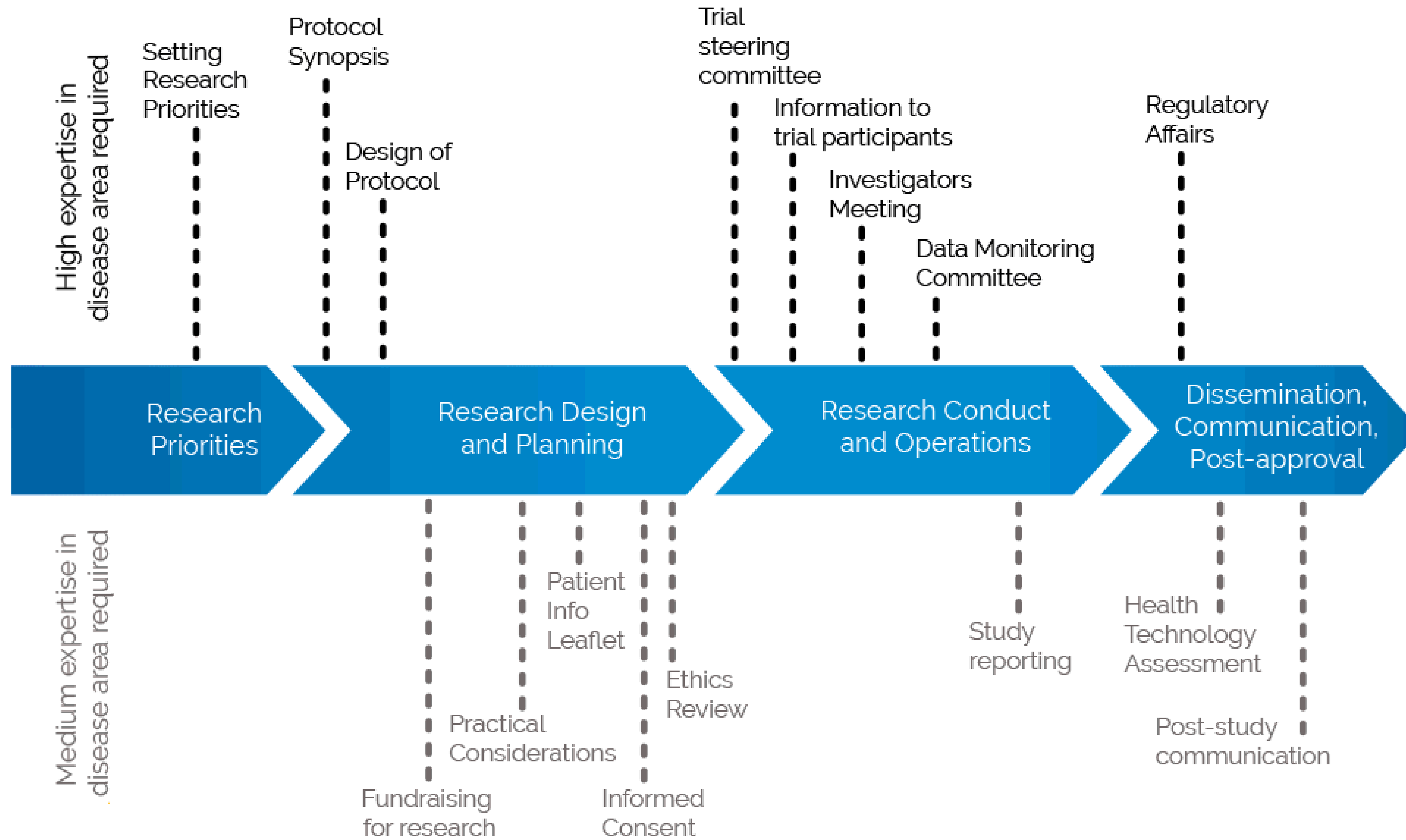


HTA agencies & committees

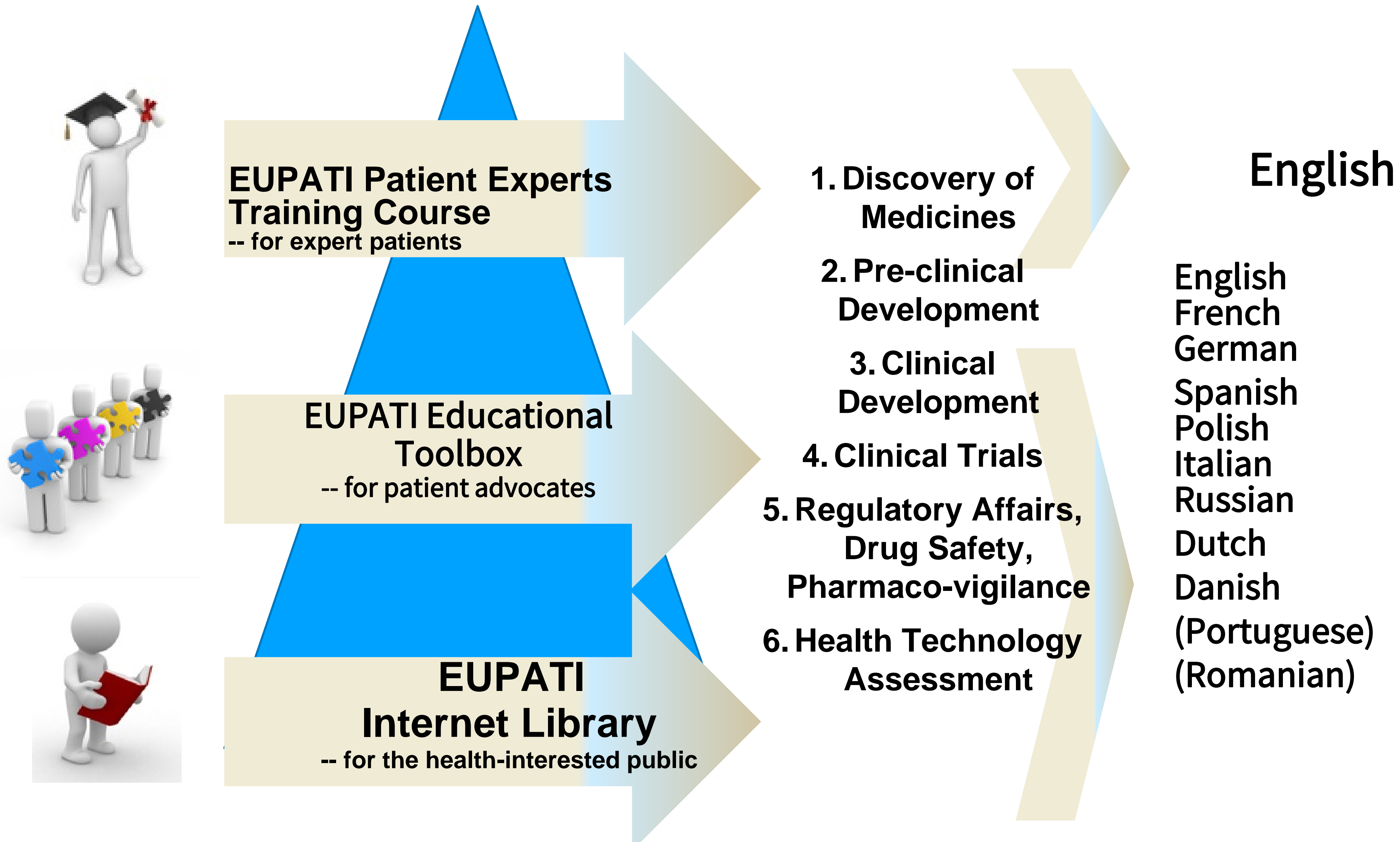


Clinical Research

Patient involvement in practice within the R&D life cycle



EUPATI develops education targeted at different levels



huManS- the book I wish I had been given when I got diagnosed

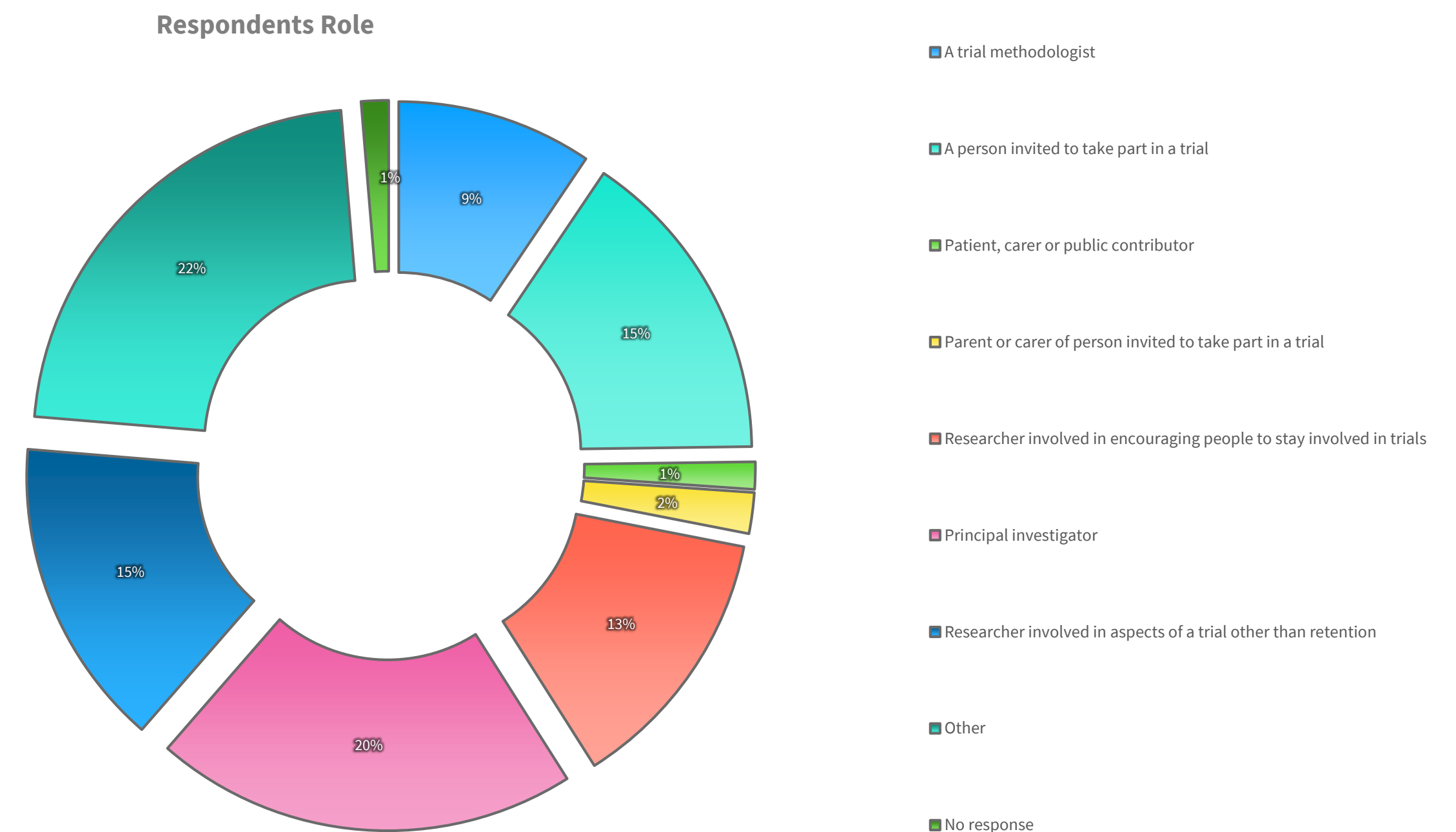


h u M a n S

**Words for the newly diagnosed from
people living with Multiple Sclerosis.**

Research Involvement: PRioRiTY II

- How can retention to trials be improved?
- What do patients think?
- What should we, as researchers, be focussed on?



Chitin

- **Cross-border Healthcare Intervention Trials In Ireland Network (CHITIN)** is a unique cross-border partnership between the Public Health Agency in Northern Ireland and the Health Research Board in the Republic of Ireland, to develop infrastructure and deliver Healthcare Intervention Trials (HITs). The HITs will help prevent and cure illness and promote improved health and wellbeing in NI, ROI and Irish cross-border areas.

It's Your Health- Own IT

- **Twitter** @Joan_JJ_Mc #PatientsInvolved
- **Facebook** Joan Jordan
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- **PROMS**- Patient Reported Outcome Measures
- **E-health**. People don't know what they don't know.