National
Multiple Sclerosis
Society

# Patient Perspectives

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# Disclosures

T. Coetzee is an employee of the National Multiple Sclerosis Society. The Society is supported by individuals, foundations and corporations, including pharmaceutical companies. Less than 5% of the Society’s annual revenue comes from pharmaceutical companies with a marketed MS treatment.

# Point 1 - Patient perspectives and attitudes to clinical trials are evolving and continue to evolve

# From passengers to co-pilots: Patient roles expand

Margaret Anderson and K. Kimberly McCleary Sci. Transl. Med. (2015)

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Science Translational Medicine AAAS

**Addressing a patient's part in advancing biomedicine**

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***1947 – Nuremburg Code adoption of the informed consent ….***

***….1984 – the HIV/AIDS movement catapulted patient needs to the forefront of research and created the force for change that dramatically altered regulatory approval processes at the U.S. Food and Drug Administration (FDA), funding formulas and emphasis at the U.S. National Institutes of Health (NIH), and the path forward for disease advocacy organizations…..***

Provided by P. Zaratin, Italian MS Society

Information about personal health situation

Self care support

Health literacy

Decision making

Communication skills

Being connected

PASSIVE

ACTIVATED

Science of Patient Input

All faith in our doctor

Passive behaviours

Helplessness

Isolation

Take action

Find information

Organise our questions

Map our options and choices

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*Adapted from David Somekh , European Health Management Association, 2016*

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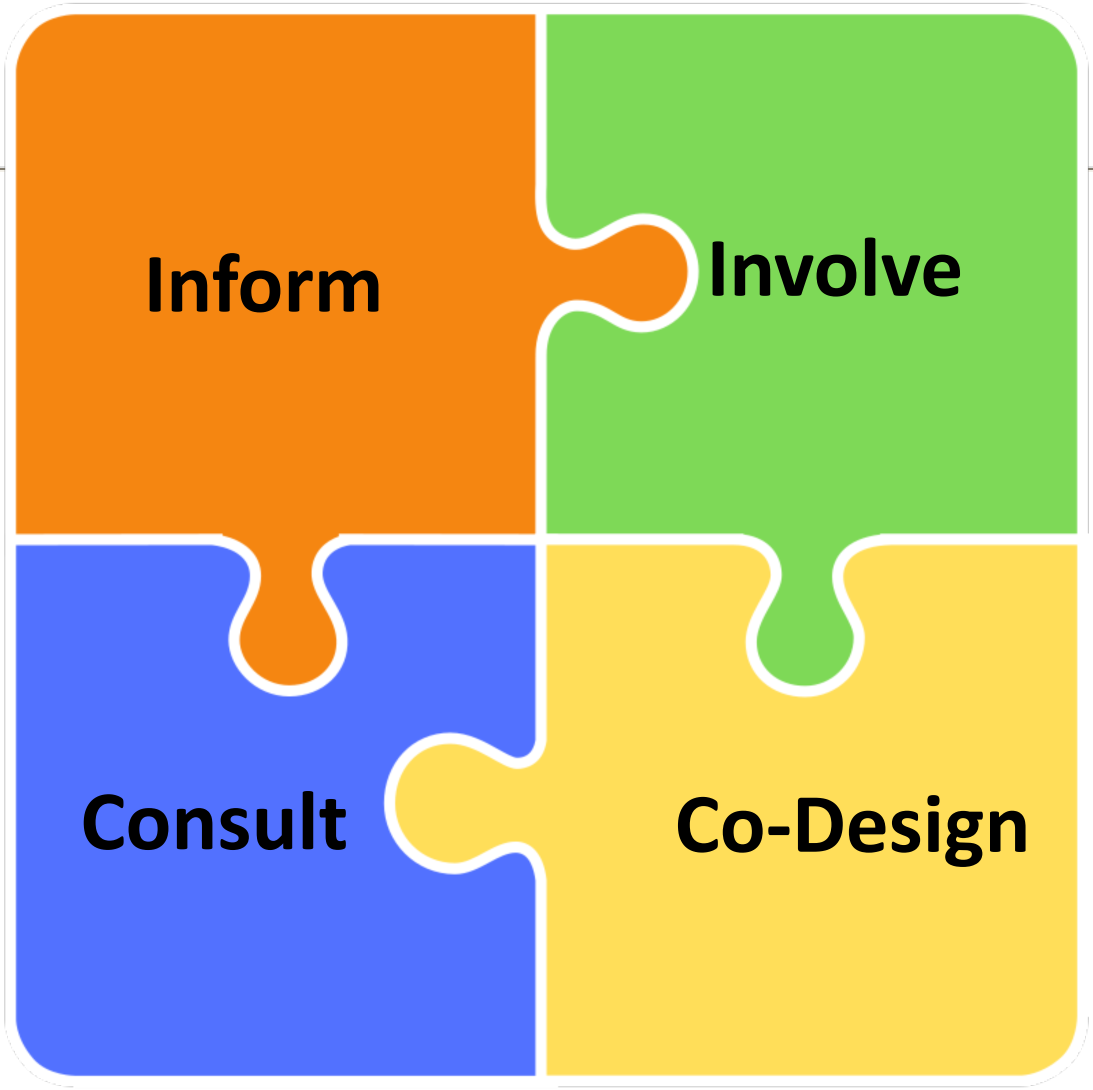
# Point 2 – We need to shift from a recruitment mindset to an engagement mindset



Inform

Involve

Consult

Co-Design

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Courtesy of P. Zaratin, Italian MS Society

# MULTI-ACT and Science of Patient Input A Collective Research Impact Framework and multi-variate models to foster the true engagement of actors and stakeholders in Health Research and Innovation

Paola Zaratin, MULTI-ACT project coordinator on behalf of MULTI-ACT Consortium

**Multi-Act**
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# Point 3 – It’s still about developing safe, effective treatments <u>and</u> ensuring affordable access matters as well.