The patient perspective in educational setting: what do patients think?

Nele Caeyers – LUPUS EUROPE
Learning objectives

• Delegates will become aware of the value of patient input in the different phases of patient care

• Delegates will learn how they can involve patients to enhance quality of care
Getting a diagnosis of a chronic illness...

- ... does not mean your IQ is reduced by 50%
Doctor – patient communication

- Active communication
- Shared decision making
- Treat-2-Target
- Self management

- Disease control
Patient ≠ subject
Patient = active participant in his care

$X = \text{one of the different stakeholders in health care}$

$P = \text{Patient}$
Use the Patient Expertise

• Individuals

• Through patient organisations
  => Patient Partners Program

• Trained Patient Experts
  => EULAR Patient Research Partners
Patient Partners Program
European League Against Rheumatism recommendations for the inclusion of patient representatives in scientific projects

M P T de Wit, S E Berlo, G J Aanerud, et al.

*Ann Rheum Dis* published online January 20, 2011
doi: 10.1136/ard.2010.135129
Recommendations

- PRP to be considered for all research projects and development of recommendations and guidelines
- PRP to be involved in all phases of the projects
- A minimum of two PRP in each project
- Identification of potential PRP using clear view on expectations
- Communication skills, motivation, assertiveness in team setting
- Principal Investigator (PI): encourage contribution
- PI: provide sufficient information and training
- Contribution of PRP should be recognised
Patient Research Partners

- Trained people with a chronic condition (RMD)
- Specific skills
- Specific expertise: experience with chronic condition differs from health care providers
- Expertise on different levels: physical, but also social, psychological, economical, ...

- Matchmaking: what is needed, what is offered?
Reference cards and Brochure

Patient Involvement in Research
A way to success

The reference cards explained

eular

9th Annual European CME Forum - Amsterdam, November 2016
Reference cards and Brochure

- Cards: Tips and practical information for both researchers and patient research partners

- Brochure: to explain the different steps of patient involvement in more detail for all parties involved
Research in a lay version

EULAR RECOMMENDATIONS
Managing the use of glucocorticoid therapy in rheumatic disease

This is the patient version of the EULAR recommendations for the management of glucocorticoid medicines in people with rheumatic diseases. The original publication can be downloaded from the EULAR website: www.eular.org.


INTRODUCTION
Glucocorticoids (prednisone or prednisolone) are medicines to reduce inflammation. They are used in rheumatic diseases such as rheumatoid arthritis, polymyalgia, lupus and vasculitis for a long time.
What is there to learn from patients?

- Living with a chronic condition 24/7, patients develop a unique expertise which differs from the professional’s knowledge.
- Involving patients in care means also listening to them and learn from their day to day experiences.
- Using the insights of all parties involved leads to a higher quality of care in the end.
Thank you

- Questions?
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