



# European Forum for Research in Rehabilitation (EFRR) Saturday 27<sup>th</sup> May 2017

Expert Panel Discussion Round Table  
**Priority Research Questions**

**#EFRR2017**



British Society of  
Rehabilitation Medicine  
Promoting quality through  
education and standards



**PEOPLE  
MAKE  
GLASGOW**

# Expert Panel for the Round Table Discussion

## **Prof. Helena Burger MD, PhD**

Medical director, specialist of PRM University Rehabilitation Institute Republic of Slovenia, Ljubljana, Slovenia

## **Dr. Susanne Weinbrenner MD, PhD**

MPHEFRR Secretary and Chief Medical Officer and Head of Department "Social Medicine and Rehabilitation", German Statutory Pension Fund, Deutsche Rentenversicherung Bund, Berlin, Germany

## **Prof. Matilde Leonardi**

EFRR Council Member and Neurologist, Paediatrician and Child Neurologist, Head of Neurology, Public Health, Disability Unit, Scientific Director Coma Research Centre and Director Italian WHO-Collaborating Centre Research Branch, Foundation IRCCS, Carlo Besta Neurological Institute, Milan, Italy

## **Dr. Gábor Fazekas MD, PhD**

EFRR Past President (2008-2009, 2011-2013) and Council Member, and Specialist of neurology and PRM, Szt. Janos Hospital and National Institute for Medical Rehabilitation, Budapest, Hungary

## **Associate Professor Kate Radford PhD**

SRR Past President, Faculty of Medicine & Health Sciences, School of Medicine, University of Nottingham, UK

Question posed to EFRR 2017 delegates  
throughout the conference:

**What is your #1 priority  
rehabilitation research question?**

## Results: Frequency of Topics (N=35)

<b>N</b>	<b>Topic</b>
11	Interventions
10	Outcomes/ measurement
3	Partnership working
2	Access to services
2	Methodology
2	Natural history/ recovery
2	Patient experiences
1	Dissemination
1	Generalisability of findings
1	Underpinning Theory

<b>N</b>	<b>Topic</b>
11	Interventions
	Methylphenidate has been around for >25 years - improves concentration, learning engagement, and is safe - could it be bolted onto UKROC outcomes study?
	How can we improve return to work?
	How early after stroke should rehabilitation/mobilization start?
	How do we measure clinical input without burdening therapists
	How can we use goals as a rehab intervention?
	How should rehabilitation be delivered to children?
	Does intensive upper limb therapy (more than 4 hours a day) delivered for 6 weeks in the acute period after stroke result in better outcomes. (There would need to be some stratification to selection)
	How can community services support long term rehabilitation?
	Recovery after a severe acquired neurological injuries is improving. However, the prevalence of severely disabled survivors has not reduced. Facilitating functional recovery in this group is essential.
	After stroke when is the best therapeutic window taking motor recovery into account
	What are the harms/side effects of rehabilitation as an intervention?

N	Topic
10	Outcomes/ Measurement
	How do we measure rehabilitation need and rehabilitation potential?
	How do we measure and evaluate the joint effect of multidisciplinary programmes?
	Should we have a consensus about the usefulness of RCTs? Are resources better spent on other methods?
	Should we try to better define the patients who may respond to a rehabilitation intervention before large trials are conducted?
	Paediatric rehab: what are the long term outcomes of rehab?
	What are the key outcomes of rehabilitation?
	Improvement in abilities? Goal achievement? Quality of Life?
	Are there outcomes relevant to all diagnoses and across disciplines
	Can we make better use of patient reported outcome measures to monitor, support, evidence rehabilitation?
	Can/How should/ goal outcome be used to evaluate rehab outcomes?
	How to evaluate the long term (eg 6 or 12 or 24 months plus) outcomes of therapy which is frequently short term but aimed at increasing a patients ability to self-manage in the longer-term?
	How Can Patient reported outcomes benefit self-management?

N	Topic
<b>3</b>	<b>Partnership Working</b>
	What is the role/requirement of nursing input to multi-disciplinary neurorehabilitation?
	How can we as a rehab staff help the patients to become more active in a hospital stay? Can we use relatives? What the barriers?
	What is the client's role when we talk about shared understanding in rehabilitation?

<b>N</b>	<b>Topic</b>
<b>2</b>	<b>Access to services</b>
	How can we improve equity of access to rehabilitation services?
	Who are the best people to decide on how/where/ when rehab should occur?

<b>N</b>	<b>Topic</b>
<b>2</b>	<b>Methodology</b>
	Should we have a consensus about the usefulness of RCTs? Are resources better spent on other methods?
	Should we try to better define the patients who may respond to a rehabilitation intervention before large trials are conducted?



<b>N</b>	<b>Topic</b>
<b>2</b>	<b>Natural History/ Recovery</b>
	Brain injury natural history of dysarthria and recovery
	what is the impact of development on ongoing rehabilitation needs and outcomes?

<b>N</b>	<b>Topic</b>
<b>2</b>	<b>Patient/ Client experiences</b>
	Should we have more research from client's point of view?
	Stroke survivors feel abandoned after discharged from the hospital. It would be useful to do some qualitative work (patients / carers perspectives) about the care they receive, support they have when living in the community.

<b>N</b>	<b>Topic</b>
<b>1</b>	<b>Dissemination</b>
	How to disseminate research to health commissioners of therapists? - they are the people who have the power to implement research

<b>N</b>	<b>Topic</b>
<b>1</b>	<b>Generalisability</b>
	Are findings from stroke research transferable to other populations with neurological disease

<b>N</b>	<b>Topic</b>
<b>1</b>	<b>Underpinning Theory</b>
	Should we have more research from client's point of view?

# Frequency of Topics

N	Topic
11	Intervention
10	
3	
2	
2	
2	
2	
1	Dissemination
1	Underpinning Theory

No questions on:

- Relationships including intimacy
- Bladder/ bowel function?
- Health economics?
- How can we engage governments to support rehabilitation and rehabilitation research?

# Frequency of Topics

N	Topic
11	
10	Do we dare ask the “difficult” questions?
3	
2	Do we ask questions that matter to our patients/ clients and their families?
2	
2	Do we involve our patients/ clients and their families stakeholders properly to know?
2	
1	
1	Underpinning Theory

# Where to next?

The top research priority questions, together with a summary of the Round Table Discussion, will be submitted as a paper to the *International Journal of Rehabilitation Research*.

A further research priority setting initiative, involving *all* EFRR members, will be undertaken in the next two years, and results will be presented at the EFRR 2019 in Berlin.

I would like to sincerely thank all delegates who took part in this initiative, for their thoughtful and important contributions.

We will keep you posted – please join us as an EFRR member (if you haven't already done so)!

With best wishes,

Frederike van Wijck

EFRR President 2017-