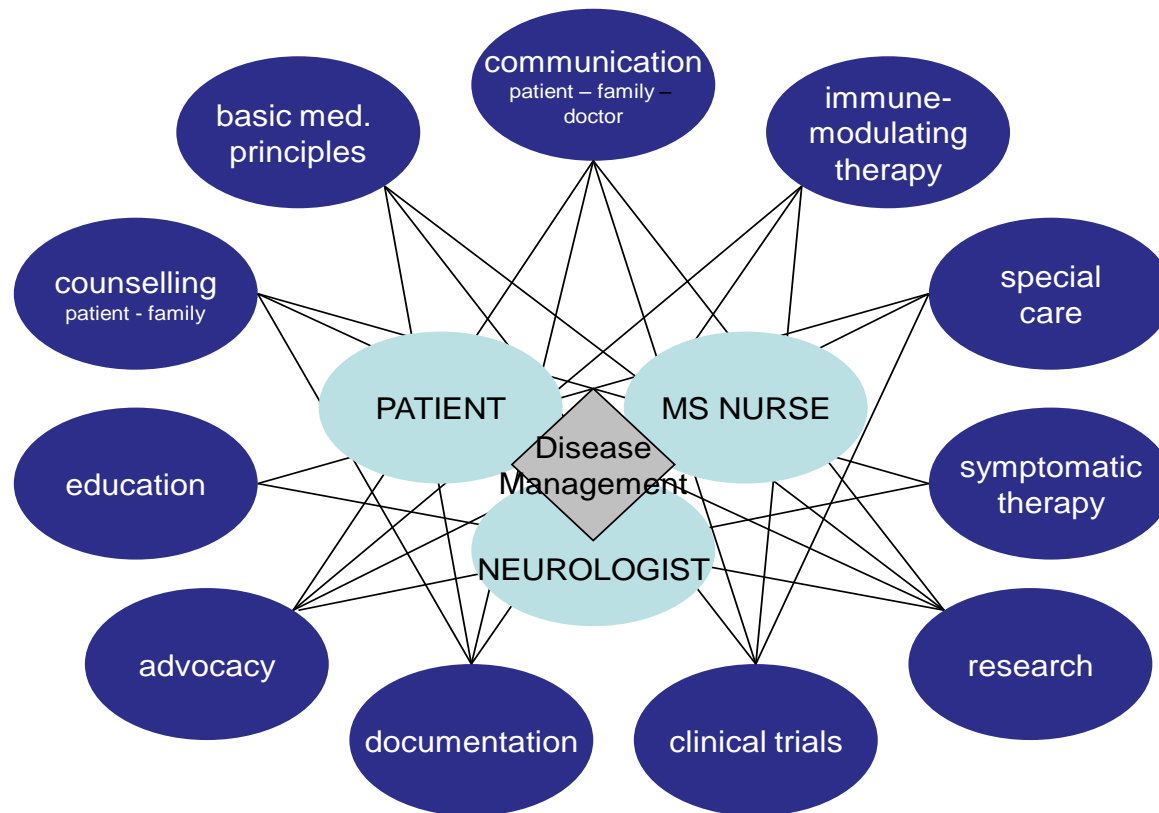


MOVING TOWARDS THE PAN-EUROPEAN UNIFICATION & RECOGNITION OF MS NURSES

Anne Winslow

Vice President, EMSP

The MS Nurse: Key Player in MDT



The development and increased education of MS Nurses will have a strong direct impact on patient outcomes, along with innovative new treatment options. This may mean the expansion of the MS Nurse role with the MDT

The Need For MS-Nurses

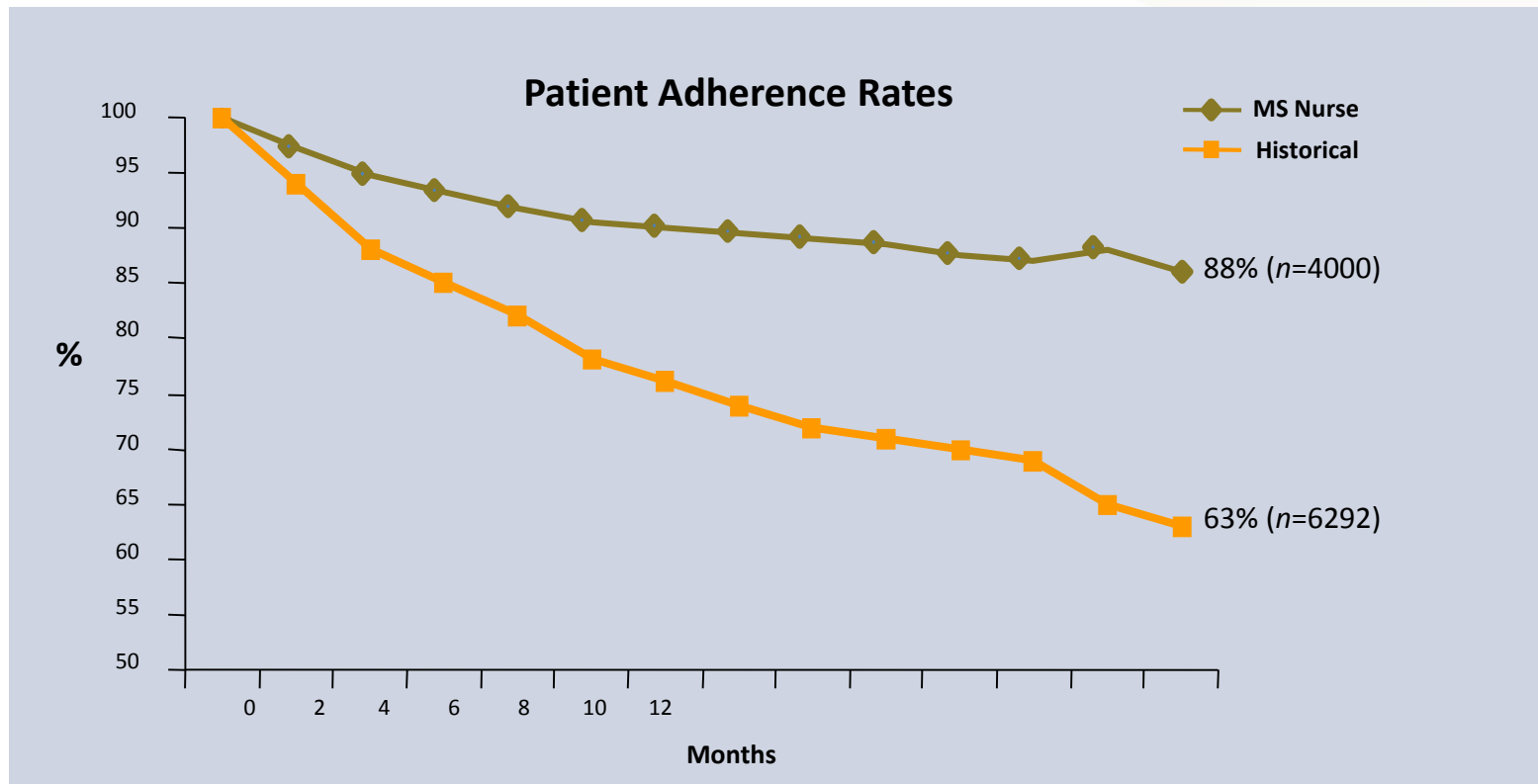
1. MS Nurses play a **central role** in long-term treatment of MS and provide significant support to persons with MS

2. Positive effect on **coping and compliance**

3. Relieves doctors from excessive workload

4. Relevant for **enhanced treatment adherence**

MS Nursing: Greater Adherence to Medication



An Evolving Role

“The link between **professionalism** and **high standard treatments** impact the QoL of people with MS (PwMS) and their capacity to continue to contribute to society as workers and as citizens is well known.”

“Yet there is **huge disparity** in the way in which people affected by MS are treated across the EU, causing **unacceptable and unnecessary lack of QoL** of MS patients, more in some member States and less in others.”



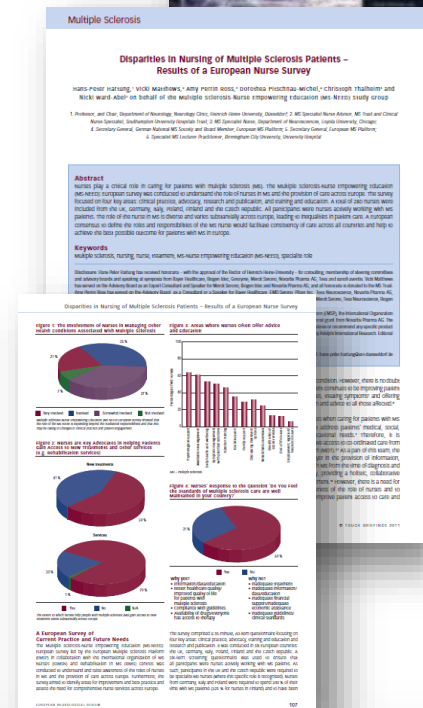
First and Largest Survey of MS Nurses Across Europe - *Multiple Sclerosis Nurse Empowering EDucation (MS-NEED): European Survey*

The MS-NEED European Survey

Objectives:

- Understand and raise awareness of the roles of nurses in MS care
- Understand the existing provision of care across Europe
- Identify areas for improvement and best practice and
- Assess the need for comprehensive nurse services across Europe

Published in the *European Neurological Review*:
Disparities in Nursing of Multiple Sclerosis Patients – Results of a European Nurse Survey



A Collaborative Effort

Collaborative effort over the last three and half years

European Multiple Sclerosis Platform
(EMSP)

- Founded in 1989, EMSP is the umbrella organisation for 38 MS societies from 34 European countries



Rehabilitation in MS
(RIMS)

- RIMS, a network of MS Centres in Europe, was created in 1991, in Milan, Italy. Today RIMS has 40 member Centres throughout Europe



International Organization of Multiple Sclerosis Nurses
(IOMSN)

- Founded in 1997, IOMSN is the first and only international organisation focusing solely on the needs and goals of professional nurses, anywhere in the world who care for people with MS



MS-NEED Steering Committee Members

Name	Affiliation	Country
Anne Winslow	Vice President, European MS Platform	Ireland
Amy Perrin Ross	Past President, International Organization of MS Nurses	USA
Christoph Thalheim	Secretary General, European MS Platform	Belgium
Michele Messmer Uccelli	Director of Projects and Services, Multiple Sclerosis Society	Italy
Nicki Ward-Abel	Board Member, International Organization of MS Nurses	UK
Lenka Pyciaková	Head Nurse, Charles University	Czech Republic
Vicki Matthews	Board Member, Rehabilitation in Multiple Sclerosis	UK
Wolfgang Köhler	Head of the Department of Neurology and Neurological Intensive Care, Fachkrankenhaus Hubertusburg & MS Centre Wermsdorf	Germany
Catherine Mouzawak	MS Nurse	France
Jörg Kraus	Neurologist, Austria	Austria
Samuel Sanchez	Rehabilitation Specialist, FEM Foundation	Spain

MS-NEED: Methodological Summary

Countries



Respondent Type

- MS Specialist Nurses / nurses seeing patients with MS

Data Collection Method

- CATI (Computer Assisted Telephone Interviewing)

Duration

- 35 minutes per interview

Questionnaire Flow

- Screener
- Clinical Practice
- Advocacy
- Training and Education
- Research and Publication
- General Questions

280 MS Nurses were polled in total for the survey

Sample and Recruitment Criteria

Country	Sample Achieved
UK	50
Germany	50
Italy	50
Poland	50
Finland	50
Czech Republic	30
TOTAL	280

Recruitment Criteria

- No involvement in any market research regarding MS in the last 3 months
- UK and Czech Republic: Specialist MS nurse
- Germany, Italy, Poland: Nurse >30% of time spent with MS patients
- Finland: Nurse >25% of time spent with MS patients
- Germany, Italy, Poland, Finland: working with MS patients as a nurse for >1 year

MS–NEED: Key Recommendations

Role of
MS Nurses
is evolving
and expanding

- Recognise MS Nursing as a specialty across Europe

Best practice
sharing can
exacerbate MS
Nurses role
within the MDT

- Need for shared MS nursing educational events/opportunities/resources across Europe in range of settings that include web technology & social media
- Ensure there is a structured, formalised and improved partnership working within current European forums and international organisations

Tools
and education
are needed

- Need for a stepwise professional development structure against an agreed European definition for MS Nursing

The Rationale.....

The pan-European unification of MS Nurses will increase quality of care for people with MS and their families and will also directly address the **European Commission's Green Paper – Modernising the Professional Qualifications Directive (2005/36/EC)** – focused on preparing for mutual recognition of a national degree (such as an MS Nurse exam) across all member states.

MS-NEED - 2012 Focus & Beyond

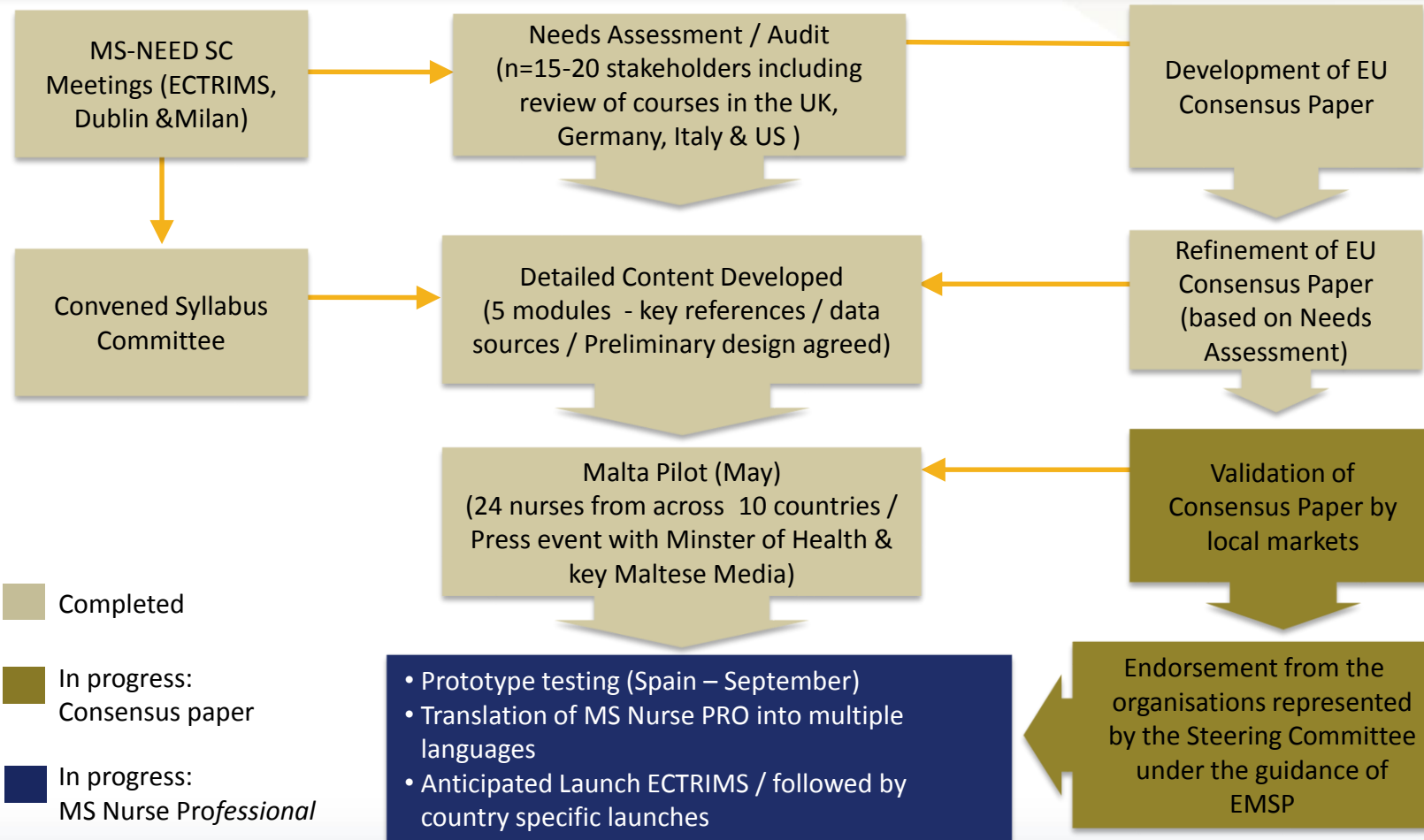
Given the inconsistencies in MS Nursing across Europe, and the many advantages of MS Nurses, there is an urgent need for pan-European unification of MS Nursing supported by a modular educational programme to increase quality of care for people with MS and their families

Setting the Standard –
MS Nurse Consensus Paper

**DIRECTLY ADDRESSES
THE EU PROFESSIONAL
QUALIFICATIONS
DIRECTIVE (2005/36/EC)**

**First and Only European CME Accredited
MS Nurse Training Curriculum –**
MS Nurse *PRO*fessional

MS-NEED – Key Accomplishment



Setting the Standard – MS Nurse Consensus Paper

Consensus Paper – Overarching Objectives

- Provide a clear definition of an MS Nurse which will act as a benchmark to enhance/align the delivery of MS care throughout Europe
- Articulate the benefits of the MS Nurse role to others to conserve and protect the MS Nurse post by acting as a resource for key stakeholders
- Drive awareness and understanding of the MS Nurse role in Europe to improve patients' access to care and treatment in order to optimise their quality of life
- Unify MS Nurses at a European level and provide an opportunity to share and learn from one another

Consensus Paper Content

- MS Care in Europe
 - Overview of current care practices based on findings from MS-NEED Survey
- Making a Difference – The MS Nurse
 - Articulate the MS Nurse key roles/ responsibilities and competencies
- The Case for MS Nurses
 - Benefits of the MS Nurse to key stakeholders including patients and healthcare professionals
- A Call to Action – Where Next?
 - Recommendations for moving forward

To be available in:
German, Italian, Russian,
Spanish, Czech and French

Where Next? Validation Process

Identify key nurse champion in each country to facilitate reviews

Engage professional medical bodies/organisations to secure their buy-in & validation (i.e. ECTRIMS, EANN, EFN, RIMS, IOMSN, EMSP)

Engage key stakeholders at a national level (local patient, nurse and medical organisations)

Present the paper to the European Commission in alignment with Green Paper, “Modernising the Professional Qualifications Directive” (2005/36/EC)

Demand for national level acknowledgement of MS Nursing as a specialist profession

First and only European CME Accredited MS Nurse Training Curriculum – MS Nurse PROfessional

Mission and Target Audience

- To provide a modular, online training curriculum to support the evolving role of European MS Nurses (in line with Consensus Paper on roles and competencies of MS Nurses)
- To increase their competency in patient / family advocacy and brokerage, health education, symptom and treatment management
 - Additionally, to develop leadership skills for the advancement of patient care
- Targeted to all MS Nurses – but with an initial focus on those starting their career in MS Nursing and may not have access to vocational training
 - The scope can then be widened to embrace the needs of experienced MS Nurses

Syllabus Committee

Committee	Affiliation	Country
Vicki Matthews (Chair)	RIMS	UK
Nicki Ward-Abel	IOMSN	UK
Jaume Sastre-Garriga	Neurologist	Spain
Kitty Harrison	MS Nurse	The Netherlands
Wolfgang Köhler	DMSG	Germany
Eija Luoto	RIMS	Finland
Roberta Motta	IMSS & IOMSN	Italy
Amy Perrin Ross	IOMSN	USA

Results from Needs Assessment

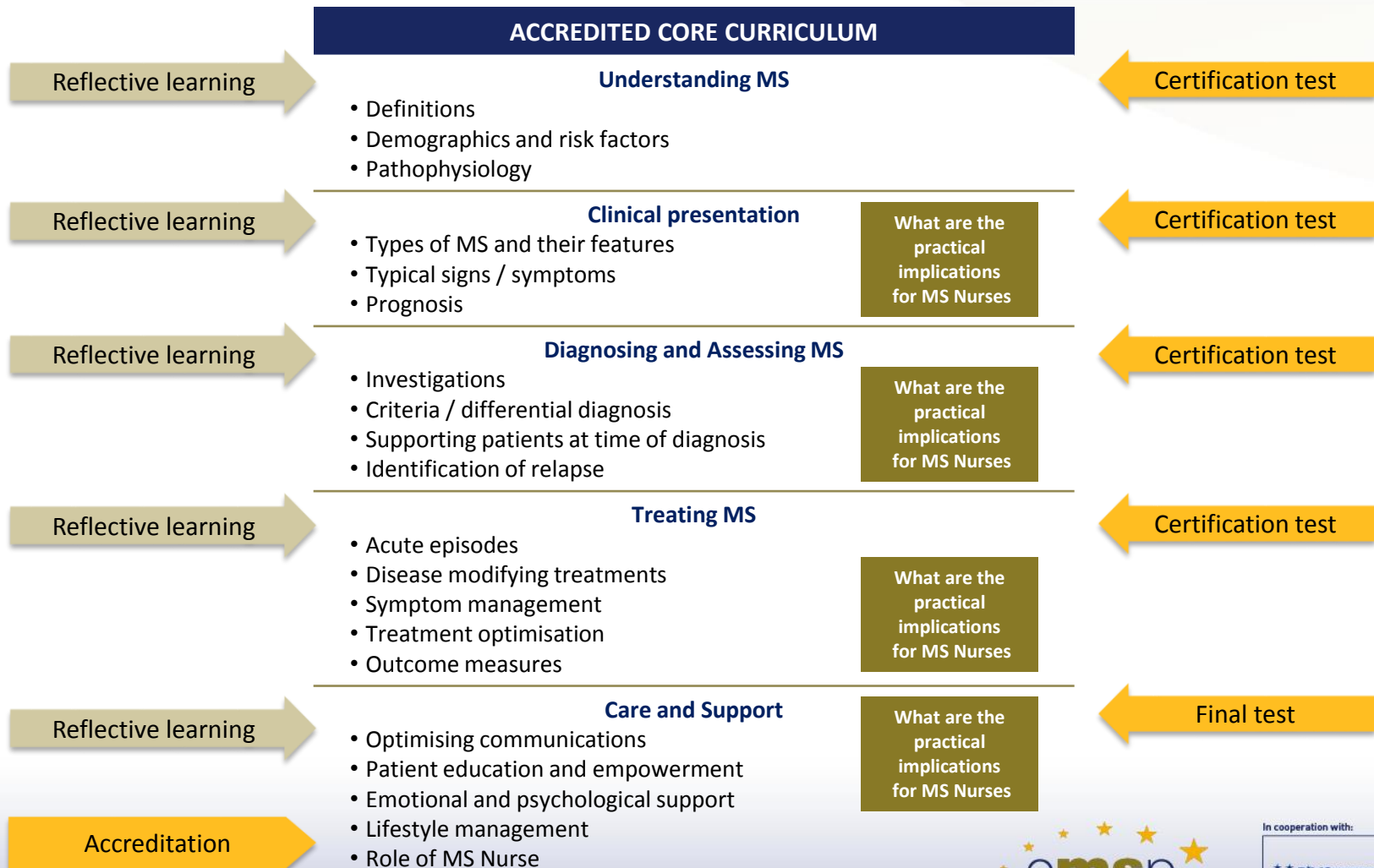
Key issue	Current status	Desired outcome
Disease background	Variable knowledge	Discuss disease trajectory with patient. Foundation in immunology to inform drug MOA, outcomes and safety
Diagnosis	Nurses mainly involved after initial diagnosis	Need working knowledge of primary diagnostic techniques in order to explain to patients post diagnosis. Relapse is key
Patient support	Critical component in all countries	Be fully conversant with psychological, psychosocial, family / carer issues and be able to provide self-help guidance
Symptom management	Key competency in most countries	Know about non-pharmacological, practical support in all areas: fatigue, rehab, pain, spasticity, incontinence, cognition workplace issues, etc
Treatment	Knowledge depends on nurses' role	Focus on therapy for symptoms. Understand biologics – particularly administration and possible ADE Benefit: risk

Needs Assessment conducted to inform the direction, structure, content and format of the MS Nurse PROfessional programme

Results from Needs Assessment *(cont'd)*

Key issue	Current status	Desired outcome
Clinical outcomes	Very little emphasis at present	Be conversant with disease outcomes, assessment criteria. Validates role of nurses when improved. Health economics of care delivery
Service development	Variable awareness /implementation	Patient advocacy (psychosocial, workplace) Patient tuition (1 on 1; group) Teaching other staff
Personal development	Individually instigated	Communications, leadership / management; teaching. Role of MS Nurse

Framework for MS Nurse PROfessional



Accreditation and Endorsement

- Curriculum to be accredited by the UK Royal College of Nursing (RCN)
 - RCN will proactively assist with submitting the programme to other European accrediting bodies for recognition and approval in target countries
 - RCN will facilitate discussions regarding higher level of education qualification (Diploma etc)
- European Association for Neurosciences Nurses (EANN) will officially endorse the activity
- Accreditation also being sought from the International Council of Nurses (ICN)



MS-NEED Malta Pilot – Building Blocks

Malta Pilot Objectives

Created a forum to stimulate discussion and gather feedback on:

- MS Nurse Consensus Paper:
 - Evaluated the Consensus Paper to ensure clinical relevance / ‘real world’ application at a basic level
- MS Nurse *PROfessional*:
 - Tested the core scientific content that will form the foundation level of the MS Nurse *PROfessional* curriculum

Nurse Participants from Across the World

Pierangela Riani (Italy)	Dr Hala Darwish (UAE)
Lenka Pyciakova (Czech Republic)	Margaret Maguire (Ireland)
Jana Becvarova (Czech Republic)	Mary Blake (Ireland)
Megan Burgess (UK)	Marisa Vella (Malta)
Wendy Hartland (UK)	Catherine Bugeja (Malta)
Jane Fowler (UK)	Silvana Mangion (Malta)
Andrea Gertz (Germany)	Alexandra Apap (Malta)
Heidi Schilling (Germany)	Catherine Mouzawak (France)
Franziska Lipske (Germany)	Kitty Harrison (Netherlands)*
Roseline Iqbal (Belgium)	Eija Luoto (Finland)*
Jan Verlinden (Belgium)	Chrysa Chrisovitsanou (Greece)*

22 nurses from
12 countries

*Participating remotely

Malta Pilot - Outcomes

Outcomes:

- Robust insights and feedback gathered on the MS Nurse PROfessional training programme and the European Consensus Paper on MS Nursing
- Empowered key nurses from across Europe that are willing to act as advocates to support collaborative steps towards the unification and recognition of the MS Nurse
 - **Initiated steps towards the establishment of the first European MS Nurse network organisation**

Close & Next Steps

Next Steps

- Spanish Pilot – September (Pending review/outcomes from Maltese pilot)
- Programme and Consensus Paper to be translated and validated nationally – May – June
- Anticipated launch – ECTRIMS 2012 / October

Thank You