



# MS Nurse Professional

A pan European MS nurse community and e-learning curriculum

 Join today via [www.ms nursepro.org](http://www.ms nursepro.org)





# MS Nurse PRO

Offers opportunities for Professional Development AND Peer Group Support

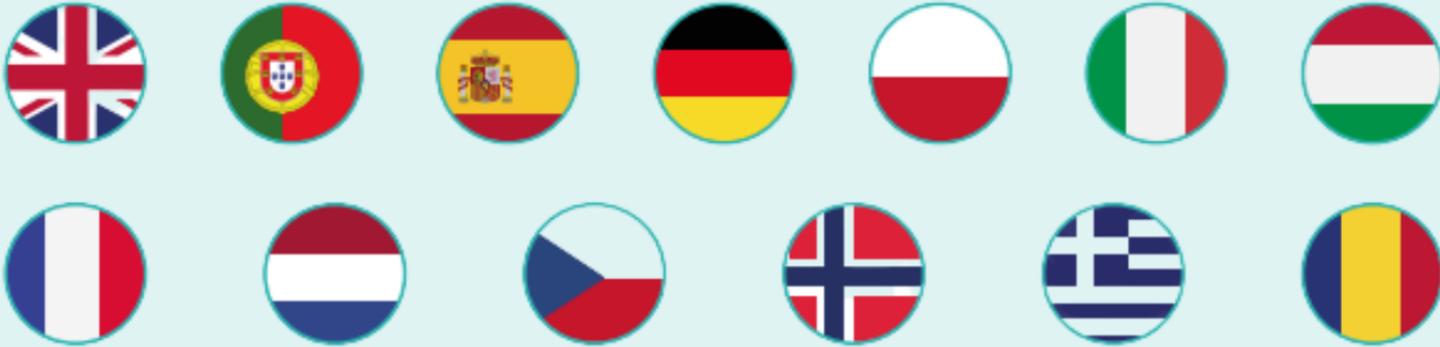
- **7 interactive courses covering different aspects of MS care**, from the basis to treatment or rehabilitation
- Developed and supported by **internationally renowned experts**
- Accredited and endorsed by **national and international nurse and MS organisation**
- **E-community for nurses to share knowledge, skills, challenges and questions.**
- **Free** for clinical health care practitioners
- In **13 different languages**



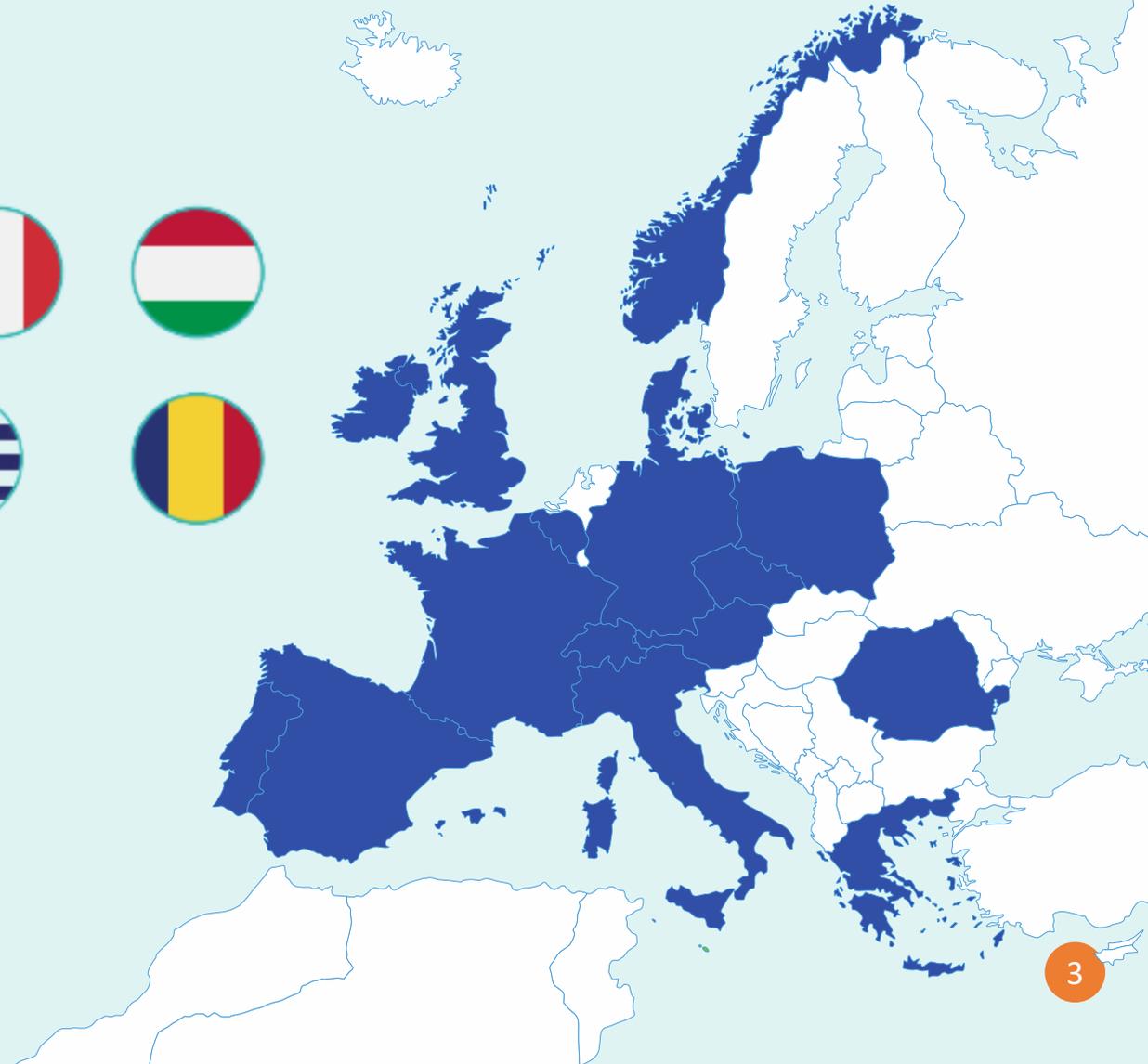


# Available in 13 languages and actively promoted in 17 countries

## 13 Languages (first 5 Modules)



6<sup>th</sup> Module on rehabilitation: English ,  
Portuguese, Spanish, Italian and Romanian  
7<sup>th</sup> Module on research: English





# The impact of MS Nurse PRO



**97%** of nurses that considers the training as relevant for their day-to-day job\*

**62%** of nurses that confirmed the training has positively changed their MS nursing practice\*



*"The MS Nurse PRO e-learning really increased my confidence to answer patient's questions. The training also improved my dialogue with other nurses and doctors."*



# The courses



Understanding MS



Clinical Presentation



Diagnosis & Assessment



Treatment



Care & Support



Rehabilitation



Research in  
MS nursing practice



# Course 7: Research in MS Nursing Practice

The course offers nurses a clear understanding of the **value of research, why it is important in MS nursing** and how it can be **implemented in clinical practice** to improve patient outcomes.

## **The course includes:**

-  **Testimonials** from research nurses describing their roles and the challenges they encounter
-  **Examples of real-world** nursing research stories
-  **Nursing tips** to help you understand the research processes and ways in which this can be **implemented in practice**

Supported by:  
**ECTRIMS**  
EUROPEAN COMMITTEE FOR TREATMENT  
AND RESEARCH IN MULTIPLE SCLEROSIS



# Join the ever-growing community of MS Nurses

➤ Join today via  
[www.msnursepro.org](http://www.msnursepro.org)



# Future perspectives of MS nursing from a neurologist view

Joerg Kraus, MD  
Zell am See, Austria



# Agenda

- Where do we come from?
- What is the current role of MS nurses?
- What does MS nurse PRO provide?
- Future perspectives



# Agenda

- Where do we come from?
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# Where do we come from?

- Before 1990s:
  - No approved but rather experimental disease modifying treatments (azathioprine, cyclophosphamide)
  - Focus on relapse and symptomatic treatment
  - ⇒ Rather difficult interactions between MS patients and health care professionals
- 1990s:
  - Implementation of the first treatment options in MS
  - All were injectables (interferons, glatiramer acetate)
  - ⇒ First role of MS nurses:  
To assist patients for injections (Central Europe point of view)



# Where do we come from?

- 2000s:
  - Natalizumab (i.v.) and first oral treatments were introduced
  - Classical role of MS Nurses was questioned (no injectables)
  - ⇒ Role of MS nurses changed to a “co-therapeutic MS specialist” for treatment / lab intervals / side effects / questions of patients (dependent on the respective setting/ country)
  - MS nurse Pro was established
- Since then:
  - Many new treatments came to market
  - Rare / severe side effects occurred



# Agenda

- Where do we come from?
- **What is the current role of MS nurses?**
- What does MS nurse PRO provide?
- Future perspectives



# What is the current role of MS nurses?

- MS Nurses work hand in hand with neurologists
- Handling / prevention of rare / severe side effects
- Handling of complicated therapy protocols / frequent lab controls
- Support of patients' life events (family planning, pregnancy...)
- Handling of comprehensive study protocols

=> Improving quality of life of persons with MS



# What is the current role of MS nurses?

- 770 Pubmed hits for “Multiple sclerosis nurse” (1948 to Oct 2022)
- [12,445 hits for “Multiple sclerosis treatment” (1964 to Oct 2022)]
- 142 review articles for “Multiple sclerosis nurse”
  - Approx. 50% about other diseases (e.g., systemic sclerosis)
  - The rest on different roles of MS nurses:
    - Scientific studies (sleep, cannabis use...)
    - Urinary tract infections
    - Cognitive screening
    - Organisation .....



Contents lists available at [ScienceDirect](#)

## Multiple Sclerosis and Related Disorders

journal homepage: [www.elsevier.com/locate/msard](http://www.elsevier.com/locate/msard)



Review article

### The role of the clinical nurse specialist multiple sclerosis, the patients' and families' and carers' perspective: An integrative review

Michelle MEEHAN<sup>a</sup>, Owen DOODY<sup>b,\*</sup>

<sup>a</sup> *University Hospital Coventry and Warwickshire, United Kingdom*

<sup>b</sup> *Health Research Institute, Department of Nursing and Midwifery, University of Limerick, Ireland*



- British / Irish review article
- Systematic search of nine databases
- Findings from the 17 studies were extracted, synthesised and analysed thematically



Review article

## The role of the clinical nurse specialist multiple sclerosis, the patients' and families' and carers' perspective: An integrative review

Michelle MEEHAN<sup>a</sup>, Owen DOODY<sup>b,\*</sup>

- Three themes emerged:
  1. MS clinical nurse specialist (CNS) as a longitudinal care co-ordinator
  2. A bespoke care provider
  3. An expert resource
- The findings suggest a strong desire for the MS CNS to be a leading health care professional to meet the needs of patient, family, and carer



# What is the current role of MS nurses?

## Conclusion:

- Further evidence is required to explore the variability of the disease and the progressive effect and impact of cognitive decline on MS patient, families and carers in order to meet their fluctuating and often complex needs
- Findings from the review suggest a multifaceted role, and additionally, the needs of patients, families and carers are difficult to define as they vary over time as the disease progresses



# The Multiple Sclerosis Care Unit

Per Soelberg Sorensen, Gavin Giovannoni, Xavier Montalban,  
Christoph Thalheim, Paola Zaratin and Giancarlo Comi

*Multiple Sclerosis Journal*

2019, Vol. 25(5) 627–636

DOI: 10.1177/  
1352458518807082

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## **Table 1.** Why we need comprehensive MS Care Unit to optimize treatment.

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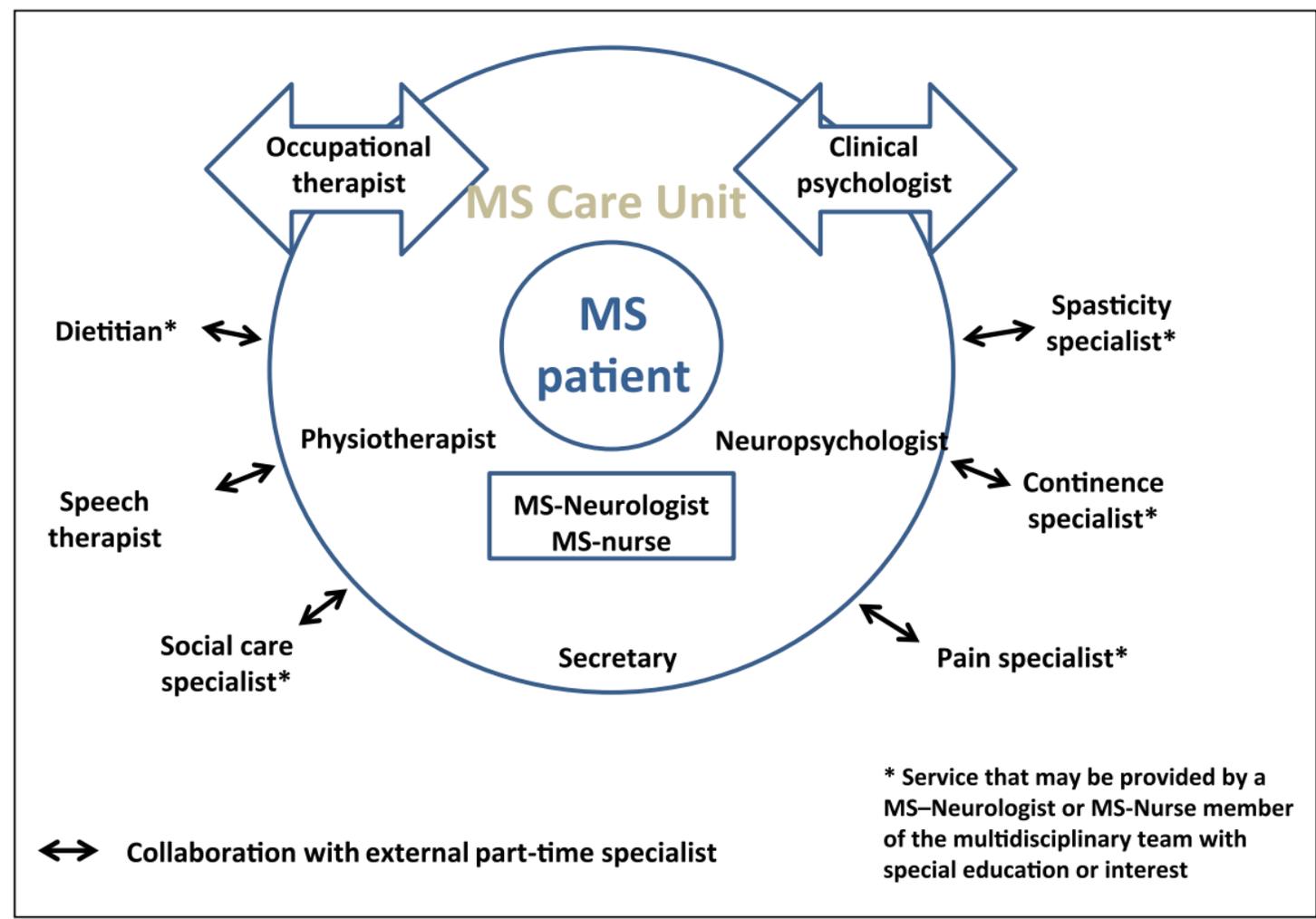
- Disease and treatment complexity
  - Early diagnosis
  - Shortage of MS neurologists
  - Selection of treatment strategies
  - Offer timely the entire spectrum of interventions
  - Patient involvement in the process of decision making
  - Appropriate monitoring
  - Risk minimization
  - Integration of competences
  - Continuity of the assistance
  - Contribution to the post-marketing refinement of drug profile
-



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**Figure 1.** Minimum requirements for a multidisciplinary MS Care Unit.



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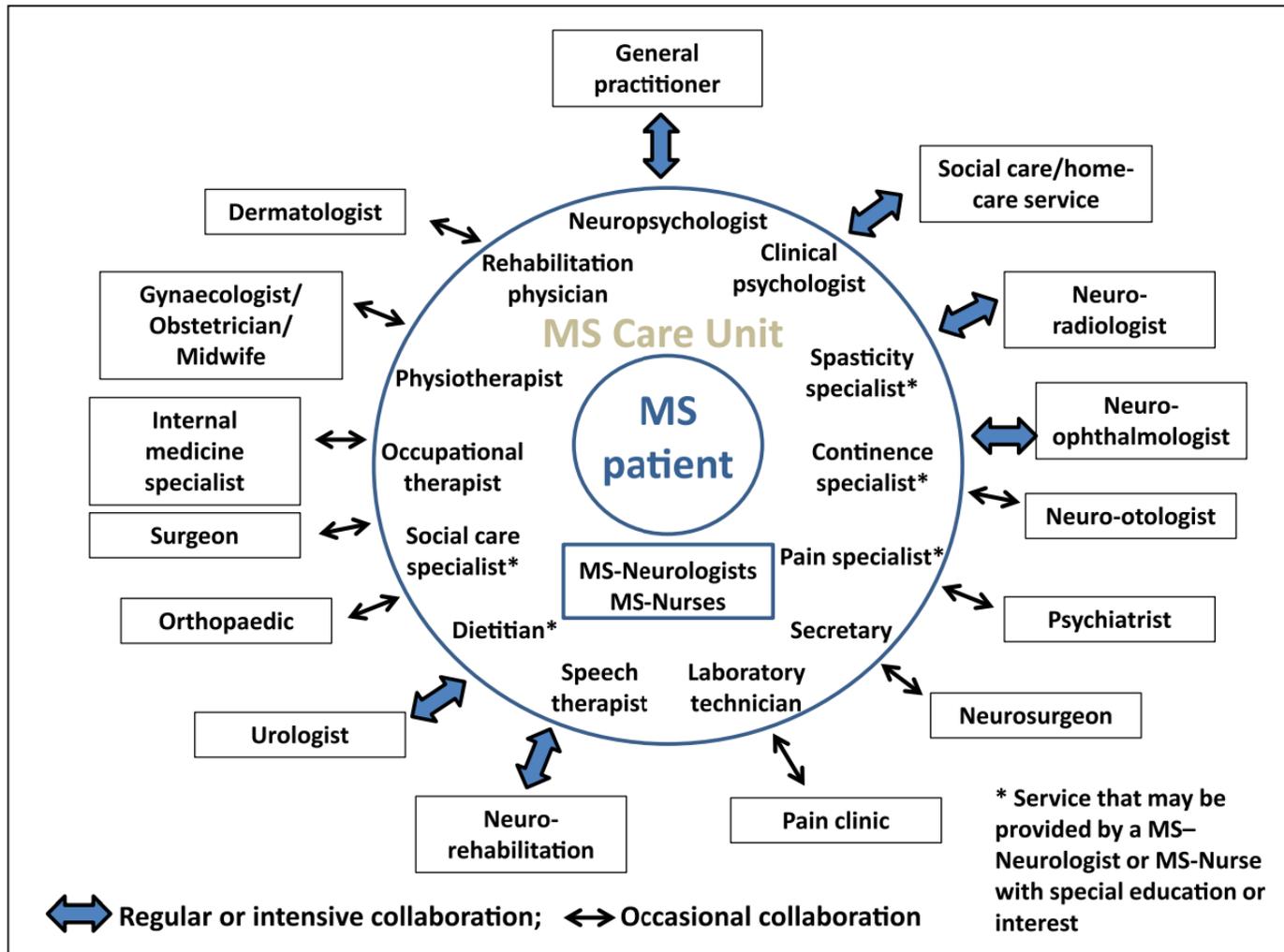


Figure 2. Organization of the fully developed integrated multidisciplinary MS Care Unit.



# What is the current role of MS nurses?

- All the positive chances concerning
    - new treatments
    - new scientific insights of the importance of lifestyle, exercise, etc.,
    - the growing importance of the role of the nurse within the multi-disciplinary care team
    - the required competences and skills have changed
- > Need for lifelong learning
- > Research on MS nursing driven at least particularly by neurologists



# Agenda

- Where do we come from?
- What is the current role of MS nurses?
- **What does MS nurse PRO provide?**
- Future perspectives

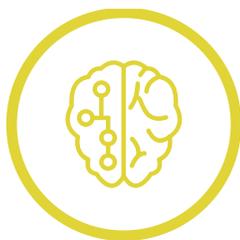


# CPD: Foundation programme

The first and only European and accredited nurse training curriculum on Multiple Sclerosis.

Each completed module leads to obtaining a certificate, that can be printed and emailed.

Each completed module gives you an online badge to show your expertise to peers and colleagues.



Understanding MS



Clinical Presentation



Diagnosis & Assessment



Care & Support



Treatment



The Foundation Programme is  
**accredited for 30 International Continuing Nursing Education Credits**  
by the International Council of Nurses and  
**20 learning credits by the Birmingham City University (United Kingdom)**



# Opportunities for peer group support

**+600**

new members yearly from  
all regions of the world

**+300**

completers of the Foundation  
Programme annually

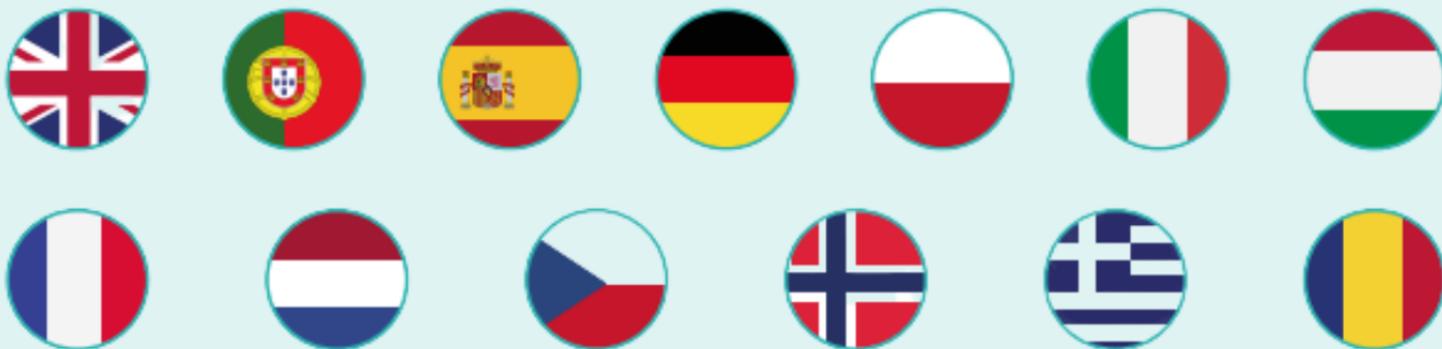
**+4000**

active users



# Available in 13 languages and actively promoted in 15 countries

## 13 Languages (first 5 Modules)



6<sup>th</sup> Module on rehabilitation: English ,  
Portuguese, Spanish, Italian and Romanian  
7<sup>th</sup> Module on research: English



# Certificates of completion and accreditation

The institutions that provide accreditation for our Foundation Programme



MS Nurse PRO is endorsed by over 25 national and international organisations





# Agenda

- Where do we come from?
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- What does MS nurse PRO provide?
- **Future perspectives**



# Future perspectives – in general

- Shortage of people working in health care institutions (nurses, doctors...) but increasing demand of care
  - Shortage of further resources
  - Increasing bureaucracy
  - Demand of productivity increase: nurses / doctors will have to care for a higher caseload than today
  - Digitalisation
- ⇒ Demand of more independently working / additionally qualified nurses



# Future perspectives – in MS

- Potentially even more elaborated MS treatment options will come
  - Therefore growing importance of a multidisciplinary approach and the central role of MS nurses
  - Further new tools (besides medication)
- ⇒ Need for more education



# Future perspectives – MS Nurse PRO



## Rehabilitation

From goal setting to the different types and methods of rehabilitation

- Available in English, Spanish, Portuguese, Italian, Romanian
- Soon available in further languages



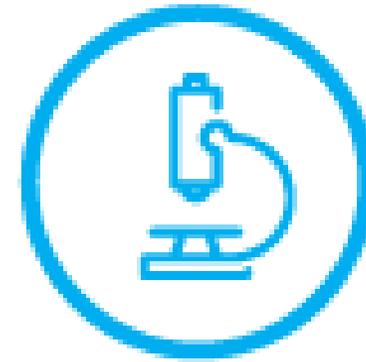
# Future perspectives – MS Nurse PRO

- Updates on different modules
  - Comprehensive update on treatment module
  - Highlighting the evolving role of the MS nurse
- ⇒ Piet Eelen's presentation



# CPD: Advanced Modules

- Completely new module
  - Important future role of MS nurses
  - Publications on MS Nursing should not predominately be provided by neurologists
- ⇒ See Amy Perrin Ross's presentation



## Research in MS Nursing Practice

From understanding the value of research to its implementing in clinical practice

**Thank you very much for your attention!!!**





# This project is currently co-funded by



And receives in kind contribution from 

Since 2012 has received funding from the following supporters.



**Thank you very much for your attention!!!**



# **MS treatment**

## **The evolving role of the MS nurse**

**Piet Eelen RN, MSc**  
**Melsbroek, Belgium**



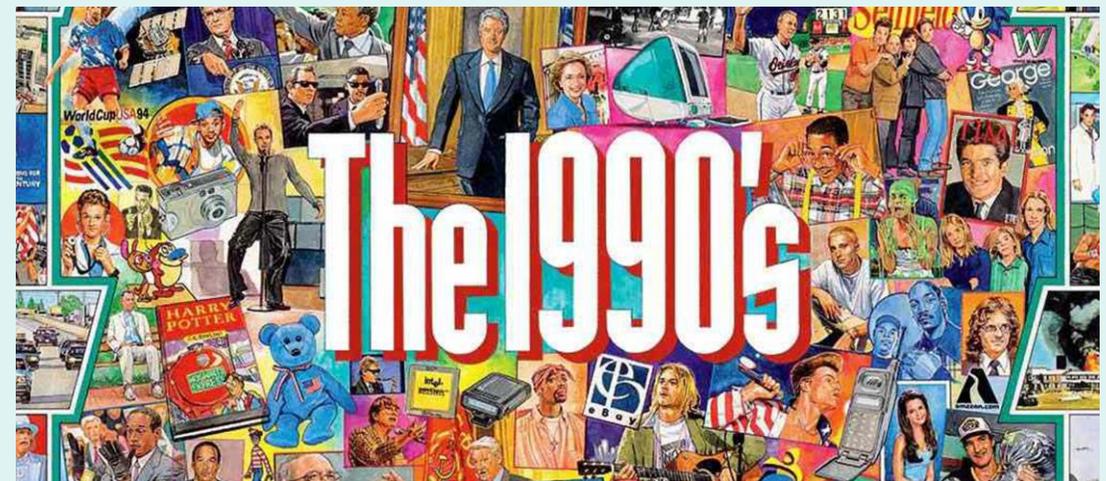
# MS treatment and the evolving role of the MS nurse

- MS nurse care from the 90's
- Changing points of interest and new insights in 2020's
- Future challenges and possible pitfalls



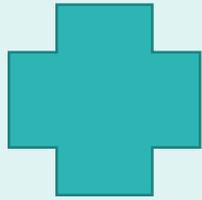
# Changes in nursing

- Reactive nursing: **‘To take care of’**
- Pathology oriented symptomatic treatment
- Limited information, education and training
- Role of nursing
  - Supporting
  - Coaching
  - Educating injections
  - Compliance
  - Managing burden; ISR and FLS





# Changes in health care



- Patient centered care
- MS Care Unit



- Increasing shortage of caregivers in the coming years, especially nurses

- Increase of caseload per nurse / doctor



# Changing points of interest and new insights

## The Evolving Role of the Multiple Sclerosis Nurse An International Perspective

Therese Burke, RN, MSCN; Sara Dishon, MPA; Lynn McEwan, NP, MScN, CNNc, MSCN;  
Jennifer Smrtka, ANP-BC, MSN, MSCN

*A greater understanding of the pathogenesis of multiple sclerosis (MS) and the need for treatments with increased efficacy, safety, and tolerability have led to the ongoing development of new treatments. The evolution of treatments for MS is expected to have a dramatic impact on the entire health-care team, especially MS nurses, who build strong collaborative partnerships with their patients. MS nurses help patients better understand their disease and treatment options, facilitate the initiation and management of treatment, and encourage adherence. With new oral therapies entering the market, the potential for increased efficacy, tolerability, adherence, and convenience for patients is evident. However, the resulting change in the treatment paradigm means that the skill set required of an MS nurse will inevitably expand. There will be a growing need for professional training and development to ensure that nurses are familiar with the wider range of treatments and their specific modes of action, dosing schedules, and benefit/risk profiles. In addition, the MS nurse's role will expand to include management of the complex monitoring needs specific to each therapy. This article explores how the role of the MS nurse is evolving with the development of new MS therapies, including novel oral therapies. Int J MS Care. 2011;13:105–112.*



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journal homepage: [www.elsevier.com/locate/msard](http://www.elsevier.com/locate/msard)



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## The role of the clinical nurse specialist multiple sclerosis, the patients' and families' and carers' perspective: An integrative review



Michelle MEEHAN<sup>a</sup>, Owen DOODY<sup>b,\*</sup>

<sup>a</sup> University Hospital Coventry and Warwickshire, United Kingdom

<sup>b</sup> Health Research Institute, Department of Nursing and Midwifery, University of Limerick, Ireland

### ARTICLE INFO

**Keywords:**  
Literature review  
Clinical nurse specialist  
Multiple sclerosis  
Integrative review

### ABSTRACT

**Background:** MS is a common, neurological disease and its unpredictable, progressive disabling nature can have a devastating effect on patients, their families' and carers. It is therefore important that the MS Clinical Nurse Specialist develops appropriate skills, services and professional expertise to support individuals along the disease trajectory.

**Design:** An integrative literature review.

**Method:** A systematic search of nine databases; Cinahl, Medline, Scopus, Embase, Ovid, AMED, Academic Search Complete, Web of Science, PsycINFO up to January 31, 2018. Hand searching and review of secondary references also undertaken. Reporting using the PRISMA guidelines, quality appraised (Crowe Critical Appraisal Tool) and thematic data analysis approach (Braun and Clarke 2006).

**Results:** Findings from the 17 studies were extracted, synthesised and analysed thematically. Three themes emerged; the MS CNS as a longitudinal care co-ordinator, a bespoke care provider, and an expert resource. The findings suggest a strong desire for the MS CNS to be a leading health care professional to meet the needs of patient, family, and carer.

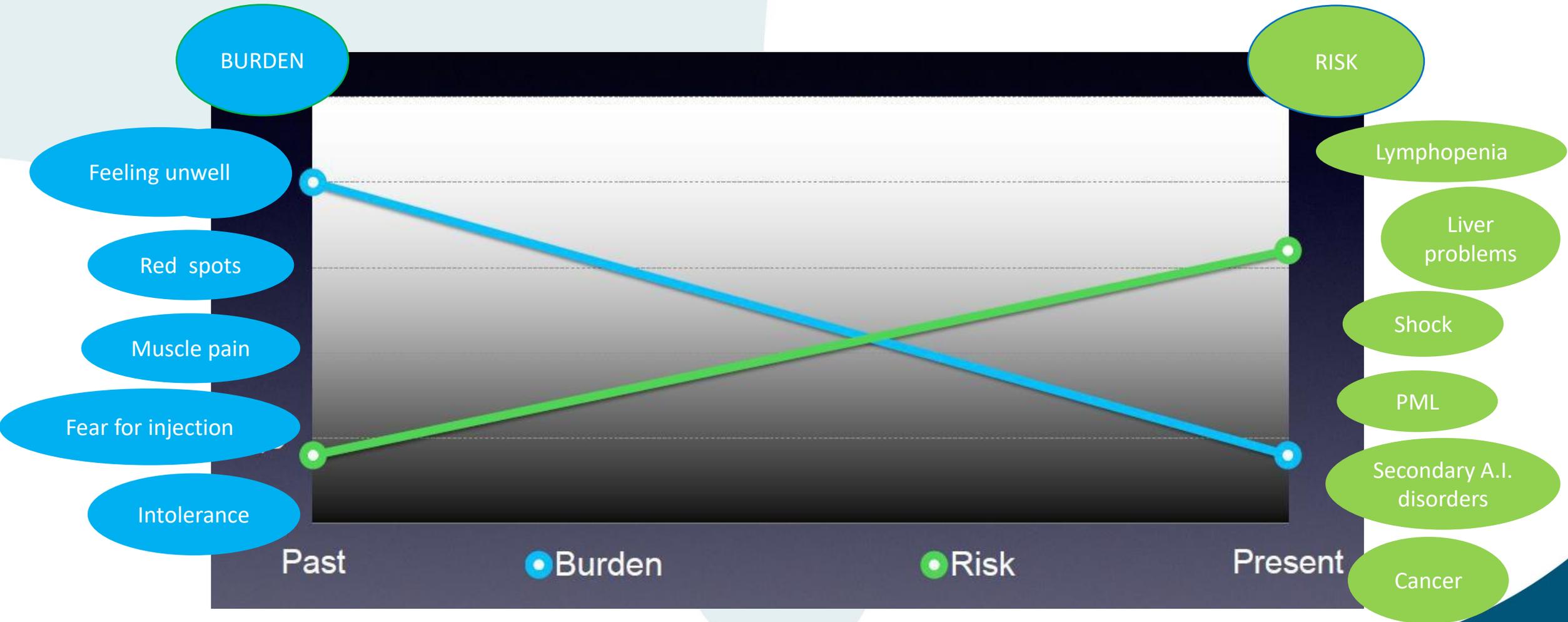
**Conclusion:** It can be argued that MS CNSs are best placed to meet the complex, variable needs individuals with MS, their families and carers. Further evidence is required to explore the variability of the disease and the progressive effect and impact of cognitive decline on MS patient, families' and carers' in order to meet their fluctuating and often complex needs. Findings from the review suggest a multifaceted role, and additionally, the needs of patients, families and carers are difficult to define as they vary over time as the disease progresses.



# Changing points of interest and new insights

- Ever increasing new molecules of DMTs
- Increasing complexity of therapy protocols
- Increasing complexity of management of SE
- Management of severe SE / monitoring Tx / vigilance
- Preventing SE
- Handling complicated therapy protocols
- Need for increased attention to adherence / compliance (e.g., Ponvory)
- Shift from burden to risk

# A shift from burden to risk



# Possible side effects and reasons for switching or stopping DMT

Gastrointestinal complaints  
Flushing  
Alopecia  
PML  
MRI progression

Biological intolerance  
Liver problems  
Lymphopenia  
Inefficacy  
Relapse  
EDSS progression

Injection site reactions  
Flu-like symptoms  
Infusion associated reactions  
Disease progression  
Inefficacy  
Pregnancy

Allergy  
Anaphylactic shock  
Neutralising AB  
Cancer / malignancies  
Thyroid disorders  
Secondary auto-immunity disorders  
Immune thrombocytopenic purpura



# Changing points of interest and new insights

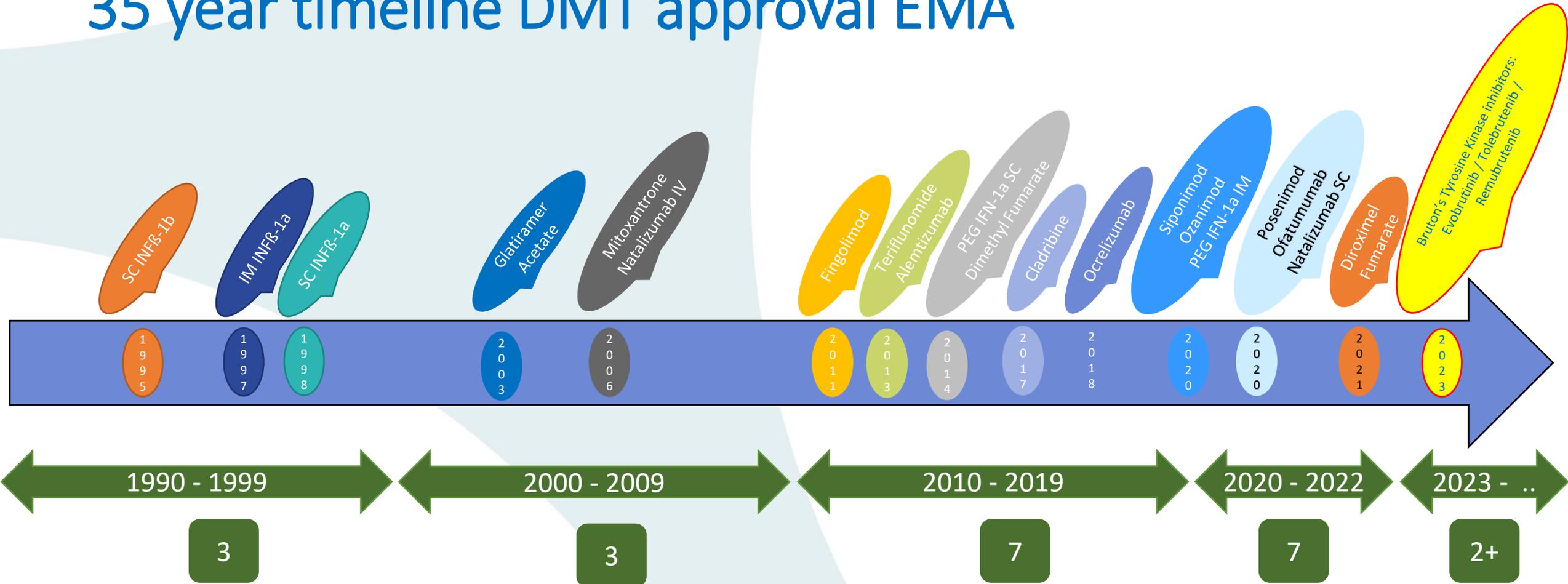
- Lifelong individualised support
  - Support needs alter through different stages
- Increasing attention for lifestyle factors
  - MD approach
  - Development of different specialisation ‘Lifestyle Medicine’
  - Aim:
    - Prevention of complications
    - Working on reserves (physical and cognitive)
- Lifelong tailormade learning



# Changing points of interest and new insights

- Shift from ‘educating and supporting’ to ‘guiding through complexity of therapy protocols and vigilant management of severe and / or rare risks’
- Lifestyle factors
  - Development of lifestyle medicine
  - P-rehabilitation
- Ever increasing new molecules of DMTs
  - Complexity of management drugs and side effects
  - Shift from burden to risk
  - DMT cards

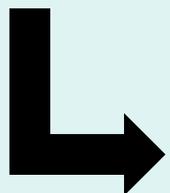
# 35 year timeline DMT approval EMA





# Why a DMT?

- RCT: DMTs have / can have an influence on:
  - Inflammation in the CNS (T1 & T2 lesions)
  - DMTs reduce the annual relapse rate
  - Impact the severity of the disease activity
  - Can have an impact on symptoms (cognition, fatigue, walking, ...)
  - Impact on progression
- Inflammation predominantly during the beginning of MS
- Which can lead from the start to irreparable damage of the CNS
- Long term effects of early treatment
- Progression leads to longitudinal changes of the immunopathological process which will lead to decrease of the efficacy of the auto-repair mechanisms

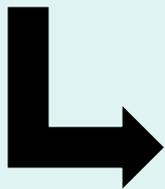


Rational for early treatment interventions in multiple sclerosis



# Why is treating MS more than a DMT?

- Limited evidence of long term effects of early treatment
- Treating MS is more than starting a DMT
- Increasing evidence of the impact of lifestyle and lifestyle interventions
  - Aiming for a complete physical, mental and social health and wellbeing
  - Respect and optimise physical and mental reserves
- Relapse treatment
- Symptomatic treatment



Rational for comprehensive approach of Multiple Sclerosis

# 20 approved disease modifying treatments

Generic name	Brand name
Interferon $\beta$ -1b SC	Betaferon
Interferon $\beta$ -1a IM	Avonex
Interferon $\beta$ -1a SC	Rebif
Glatiramer Acetate	Copaxone
Mitoxantrone	Novantrone
Natalizumab IV	Tysabri IV
Fingolimod	Gilenya
Teriflunomide	Aubagio
Alemtuzumab	Lemtrada
PEG Interferon $\beta$ -1a SC	Plegridy SC

Generic name	Brand name
Dimethyl Fumarate	Tecfidera
Cladribine	Mavenclad
Ocrelizumab	Ocrevus
Siponimod	Mayzent
Ozanimod	Zeposia
PEG Interferon $\beta$ -1a IM	Plegridy IM
Posenimod	Ponvory
Ofatumumab	Kesimpta
Natalizumab SC	Tysabri SC
Diroximel Fumarate	Vumerity

Avonex®	Interferon β-1a	Biogen (MSCRG pivotal study & Champions Extension study)
<b>Product</b>	<u>Classification</u>	Immuno Modulator
	<u>Galenic form</u>	Prefilled syringe 
	<u>Administration</u>	SC / 30 µg – 1x/week / <u>can be started without titration</u>
	<u>Storage</u>	<u>Between 2 and 8°C</u>
<b>Start</b>	<u>Laboratory</u>	CBC / <u>Liver- and kidney function</u>
	<u>Exam</u>	<u>Eliminate acute infections</u> / Check parameters / <u>if necessary MRI brain</u>
	<u>Pregnancy</u>	<u>Test before start / AC during Tx / consider to stop during pregnancy / Re-rstart after pregnancy / Breast feeding is possible</u>
	<u>Vaccination</u>	<u>Living and Not-living: No adjustments needed</u> <u>COVID: probably normal immunrespons</u>
<b>Treatment</b>	<u>Laboratory</u>	<u>Yearly FU CBC + Liver- and kidney functions</u>
	<u>Exam</u>	<u>If necessary MRI brain</u>
	<u>Tx Se</u>	FLS / ISR / <u>Depression</u> / TMA
	<u>Switching</u>	No <u>restrictive guidelines</u>



Avonex®	Interferon β-1a	Biogen (MSCRG pivotal study & Champions Extension study)
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	<u>Pregnancy</u>	<u>Test before start</u> / <u>AC during Tx</u> / <u>consider to stop during pregnancy</u> / <u>Re-start after pregnancy</u> / <u>Breast feeding is possible</u>
	<u>Vaccination</u>	<u>Living and Not-living: No adjustments needed</u> <u>COVID: probably normal immuunrespons</u>
Treatment	<u>Laboratory</u>	<u>Yearly FU CBC + Liver- and kidney functions</u>
	<u>Exam</u>	<u>If necessary MRI brain</u>
	<u>Tx Se</u>	<u>FLS / ISR / Depression / TMA</u>
	<u>Switching</u>	<u>No restrictive guidelines</u>

Plegridy® IM	PEG Interferon β-1a	Biogen
Product	<u>Classification</u>	Immuno Modulator Pegylated interferon (cfr IM versie) 
	<u>Galenic form</u>	<u>Prefilled syringe</u>
	<u>Administration</u>	125µg – 1x/ 14 days – <u>titration at the start (63µg -&gt; 94µg -&gt; 125µg) – with clips!!</u> <b><u>Not for autoinjection</u></b>
	<u>Storage</u>	2-8°C ( <u>until 30 days</u> at room T°, but outside <u>the influence</u> of light)
Start	<u>Labo</u>	CBC + <u>liver- and kidneyf°</u>
	<u>Exams</u>	<u>Check infection and parameters</u> / <u>MRI if necc</u>
	<u>Pregnancy</u>	<u>Test before start</u> / <u>AC during Tx</u> / <u>STOP at conception and during pregnancy</u> / <u>Re-start after pregnancy</u> / <u>Breast feeding is possible</u>
	<u>Vaccination</u>	<u>Living: not recommended</u> / <u>Not-living: possible</u> / <u>COVID: probably nl immuunrespons</u>
Monitoring Tx	<u>Laboratory</u>	CBC + <u>liver- and kidneyf°</u>
	<u>Exams</u>	<u>MRI if necessary</u>
	<u>Tx SE</u>	<u>SE cfr SC version (mostly after 24 tot 48 hours)</u> , but <u>less ISR</u> <u>FLS / depression / liverproblems</u> / <u>TMA</u>
	<u>Switching</u>	<u>No guidelines</u> -> <u>check re-population of lymfocytes</u>

Zeposia® po	Ozanimod	BMS
Product	Classification	Immuno-modulator Sfingosine-1-phosphate receptor modulator (S1P) S1P1 en S1P5 selective agonist (NOT on S1P3 in hart muscle) EDSS ≤ 6,5 1 <sup>st</sup> line
	Galenic form	Hard capsule of 0,92mg Available in open pharmacy Startkit: 7 capsules (4 of 0,23mg + 3 of 0,46mg) Treatment box: 28 capsules of 0,92mg
	Administration	Oral To start with titration Dose: 0,92 mg Can be taken with drinks and / or food / best on fixed moment
	Storage	Under 25°C



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	<u>Storage</u>	Under 25°C



Zeposia® po	Ozanimod	BMS
<b>Start</b>	<u>Start scheme</u>	Day 1 to day 4: 1 x 0,23mg Day 5 to day 7: 1 x 0,46mg From day 8: 1 x 0,92mg /dag
		If a dose is skipped: start <u>same titration scheme as on the initial start of Tx if interruption of:</u> ⇒ 1 day or more in the first 2 weeks of the Tx ⇒ > 7 consecutive days between day 15 and day 28 ⇒ > 14 consecutive days after day 28 of Tx



Zeposia® po	Ozanimod	BMS
<b>Start</b>	<u>Laboratory</u>	CBC / liver <sup>o</sup> / VZV ⇒ <u>Optional:</u> HBV / HCV / IGRA / JCV
	<u>Exams</u>	Eliminate acute infections / Check parameters If necessary brain MRI ECG In case of <u>cardiac history:</u> <u>cardiological evaluation</u> If <u>history of diabetes mellitus, uveitis or retina problems:</u> <u>advice ophthalmology</u>
	<u>Pregnancy</u>	Test before start AC during Tx and at least 3 months after stop Tx STOP in case of <u>conception during Tx</u> NOT during <u>breast feeding</u>
	<u>Vaccination</u>	Before start: <u>mandatory VZV if IgG are negative / at least 1 month before start / also if no data of vaccination!</u> Living: at least 1 month before start, not during Tx en NOT to 3 months after stop Non-Living & COVID : no <u>guidelines yet</u>

Zeposia® po	Ozanimod	BMS
<b>Product</b>	<u>Classification</u>	Immuno-modulator Sfingosine-1-phosphate receptor modulator (S1P) S1P1 en S1P5 <u>selective agonist (NOT on S1P3 in hart muscle)</u> EDSS ≤ 6,5 1 <sup>st</sup> line
	<u>Galenic form</u>	Hard capsule of 0,92mg Available in open pharmacy Startkit: 7 capsules (4 of 0,23mg + 3 of 0,46mg) Treatment box: 28 capsules of 0,92mg
	<u>Administration</u>	Oral To start with titration Dose: 0,92 mg Can be taken with drinks and / or food / best on fixed moment
	<u>Storage</u>	Under 25°C



Zeposia® po	Ozanimod	BMS
<b>Start</b>	<u>Start scheme</u>	Day 1 to day 4: 1 x 0,23mg Day 5 to day 7: 1 x 0,46mg From day 8: 1 x 0,92mg /dag
		If a dose is skipped: start same titration scheme as on the initial start of Tx if interruption of: ⇒ 1 day or more in the first 2 weeks of the Tx ⇒ > 7 consecutive days between day 15 and day 28 ⇒ > 14 consecutive days after day 28 of Tx



Zeposia® po	Ozanimod	BMS
<b>Start</b>	<u>Laboratory</u>	CBC / liver <sup>o</sup> / VZV ⇒ <u>Optional</u> : HBV / HCV / IGRA / JCV
	<u>Exams</u>	Eliminate acute infections / Check parameters If necessary brain MRI ECG In case of cardiac history: cardiological evaluation If history of diabetes mellitus, uveitis or retina problems: advice ophthalmology
	<u>Pregnancy</u>	Test before start AC during Tx and at least 3 months after stop Tx STOP in case of conception during Tx NOT during breast feeding
	<u>Vaccination</u>	Before start: mandatory VZV if IgG are negative / at least 1 month before start / also if no data of vaccination! Living: at least 1 month before start, not during Tx en NOT to 3 months after stop Non-Living & COVID : no guidelines yet

Zeposia® po	Ozanimod	BMS
<b>Treatment</b>	<u>Exams</u>	Parameters If necessary brain MRI In case of visual problems or ophthalmological problems in history: ⇒ Oftalmo FU after 3 to 4 months
	<u>Tx SE</u>	Infections Headache Bradycardia Breathing problems Macula oedeem
	<u>Switching</u>	Check repopulatie lymfocytien  Be aware of the longer half-life of the molecule of several months!!  Evaluate disease activity but additional immuno modulating affect of Zezosia must be taken into account before starting another DMT

Tysabri® SC	Natalizumab	Biogen	
Product	Classification	Immunomodulator	
	Galenic form	Pre-filled pen	
	Administration	2 x 150mg every 4 weeks / every month	
	Storage	2-8°C / max 24 hours at room T°	
Start	Laboratory	CBC with Lymphocytes subpopulation / liver and kidney° / HSV / JCV	
	Exams	Check infections / Parameters / MRI eventually before start	
	Pregnancy	Test before start / AC during Tx / stop preferably during pregnancy / re-start after pregnancy / not during breast feeding	
	Vaccination	<u>Living</u> : no data – no evidence / <u>Not-living</u> : no problem, probably some reduced and slower immune response / <u>COVID</u> : probably nl immune response	
Monitoring Tx	Laboratory	Half yearly: CBC + liver and kidney° + TSH + JCV	
	Exams	MRI: JCV neg: 1x/Y – JCV pos: 1x in Y 1 / Every 6m in Y 2 / Every 4m from Y 3	
2 <sup>de</sup>	Tx SE	Anaphylactic shock / Infections and parasitic diseases / ISR / Anaemia / Thrombocytopenia / ITP / PML	
	Switching	Check repopulation of lymphocytes and CBC	

Kesimpta® SC	Ofatumumab	Novartis
<b>Product</b>	<u>Classification</u>	Immuno suppressivum <u>Monoclonal anti-CD-20 antibody (epitope on B-cells)</u> ⇒ <b>B-cell therapie</b> RMS <u>Ofatumumab is a fully (100%) humanised monoclonal antibody (via DNA technology)</u> EDSS ≤ 6,5 2 <sup>nd</sup> line
	<u>Galenic form</u>	<u>Prefilled syringe</u> <u>Auto-injections</u> SC <u>With the Sensoready® Pen1 “Click-and-go”</u> <u>Available in open pharmacy</u>
	<u>Administration</u>	20mg <u>Ofatumumab</u> in 0,4ml Start via <u>titration: day 1, 7, 14 and 28, then 1 time every month</u>
	<u>Storage</u>	2-8°C ( <u>tolerance to 25°</u> ) <u>Can be kept 7 days outside of fridge and then even 7 days more in fridge !!</u>



Kesimpta® SC	Ofatumumab	Novartis
Product	Classification	Immuno suppressivum Monoclonal anti-CD-20 antibody (epitope on B-cells) ⇒ <b>B-cell therapie</b> DME



	Kesimpta® SC	Ofatumumab	Novartis
Galenic	<b>Start</b>	<u>Laboratory</u>	CBC / CRP / HBV ⇒ <u>Optionnal: liver- and kidneyf°</u> / HBC / IGRA / JCV
Admini		<u>Exams</u>	<u>Exclude acute infections</u> / Check parameters MRI
Storage		<u>Pregnancy</u>	Test before start AC during Tx STOP min <b>6 months</b> before conception Re-start after pregnancy <u>Can during breast feeding from day 3 after giving birth</u>
		<u>Vaccination</u>	<u>Living: 4 wks before start, not during Tx</u> <u>Non-living: best 2 wks before start, during TX possibly less immuun respons</u> <u>COVID: still in study, probably less immuun respons to the vaccin</u>

**INITIAL DOSES**

DAY 1    DAY 7    DAY 14    DAY 21  
NO INJECTION

**MONTHLY DOSING**

DAY 28  
START MONTHLY DOSING

**April 2022**

Week	Ma	Di	Wo	Do	Vr	Za	Zo
13						1	2
14	4	5	6	7	8	9	10
15	11	12	13	14	15	16	17
16	18	19	20	21	22	23	24
17	25	26	27	28	29	30	

1<sup>ste</sup> dosis: 1 april (start)  
 2<sup>de</sup> dosis: 8 april (week 1)  
 3<sup>de</sup> dosis: 15 april (week 2)  
 4<sup>de</sup> dosis: 29 april (week 4)  
 5<sup>de</sup> en volgende dosis: 29<sup>ste</sup> van de ma



Kesimpta® SC	Ofatumumab	Novartis
Product	Classification	Immuno suppressivum Monoclonal anti-CD-20 antibody (epitope on B-cells) ⇒ <b>B-cell therapie</b> PASC



Kesimpta® SC	Ofatumumab	Novartis
Start	Laboratory	CBC / CRP / HBV ⇒ <u>Optionnal: liver- and kidneyf° / HBC / IGRA / JCV</u>

		Kesimpta® SC	Ofatumumab	Novartis
Galenic	Exams	<b>Monitoring during Tx</b>	Laboratory	No <u>indication to do regularly controles due to 'safe' profile of side effects</u> ⇒ <u>Hospital / neurologist dependent</u>
	Pregnancy		Exams	No <u>indication to do regularly controles due to 'safe' side effects profile</u> ⇒ <u>Hospital / neurologist dependent</u>
Admini	Vaccination		Tx SE	<u>Injection related reactions – especially first 24 hours after injection and also after first injection</u> <u>Possible:</u> ⇒ <u>Redness, swelling, itching, pain</u> ⇒ <u>Headache, fever, fatigue, muscle pain, chills</u> ⇒ <u>Infections: upper airways, throat, bladder</u>
Storage		Switching		Re-population lymfocyten + <u>specific guidelines per DMT !!!</u>





# MS treatment and the evolving role of the MS nurse

- MS nurse care from the 90's
- Changing points of interest and new insights in 2020's
- Future challenges and possible pitfalls





# Future challenges and possible pitfalls of role of MS nurse

## ➤ Increasing demand of care

- Increasing complexity of treatment
- Evolution to ever expanding high-technical medication monitoring role
- Single point of contact that ensures continuity of care
- More independently working nurses
- Increased 'bureaucracy': empathy stays mandatory!
- Increasing importance of P-Rehabilitation



# Future challenges and possible pitfalls of role of MS nurse

## ➤ Decreasing offer of care

- Shortage of caregivers in the coming years, especially nurses
- Increase of caseload per nurse / doctor
- Many MS CNS roles are 'lone-roles' which can add to the stress and lead to burnout
- MS CNS support needs need to be addressed due to the complexity of MS and the ever-growing caseload



# Future challenges and possible pitfalls of role of MS nurse

- More and advanced education for nurses
  - ❑ Continuously updating knowledge of nurses
  - ❑ Need for complete and comprehensive information
  - ❑ Accessible and user-friendly information for PlwMS
  - ❑ Updates on different modules of MS Nurse Pro (1 & 2)
  - ❑ Comprehensive update on Module 4 of MS Nurse Pro
  - ❑ Enhancing network opportunities to share expertise



# Future challenges and possible pitfalls of role of MS nurse

- Inter- or multidisciplinary approach to care is needed
  - ❑ Collaborate with neurologist, rehabilitation physicians, PT, OT, SLT, SW, psychologist, dietitian, ..
- More research on the future role
- Need for more evidence of the MS nurse by nurses

# Research in MS nursing practice

Amy Perrin Ross  
APN, CNRN, MSCN  
Chicago, Illinois USA



# Research

## Research

- Systematic enquiry that uses structured methods to answer questions and solve problems
- Ultimate goal: to develop, refine, and expand a body of knowledge

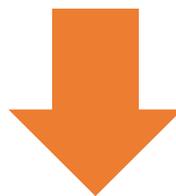
## Nursing research

- Systematic enquiry designed to develop evidence about issues of importance to the nursing profession
- Ultimate goal: to achieve better standards of care for patients and their families
  - Can also inform policy and practice decisions, shaping how care is delivered



# Research: What does it mean?

- Research is one of the main ways that nurses can evaluate, develop, and support their practice
- Research should not be thought of as an optional extra but should be placed at the very heart of all nursing practice
- Nurses are increasingly expected to understand and conduct research, and to base their professional practice on emerging evidence from research

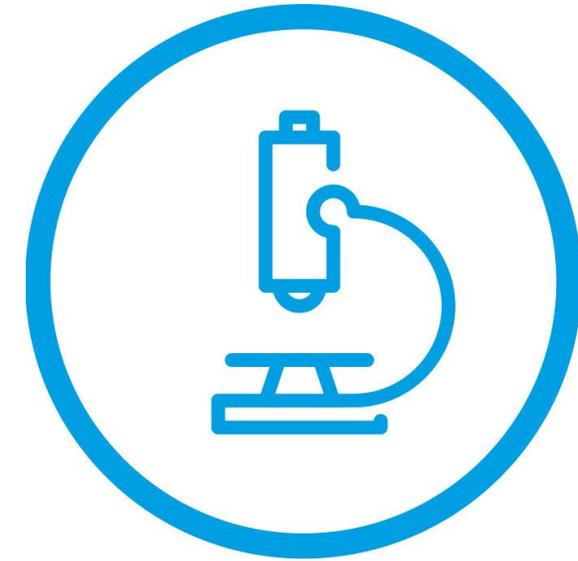


**Adopt an evidence-based practice**



# The importance of nursing research

- Evaluating nursing care is integral to the nursing profession
- Nurses continually need to access and evaluate new information, and incorporate findings into clinical decision-making
- Nurses know how to ask questions and they know which questions need answering
- Research is vital in order to develop new innovations to improve ways of working
- An understanding of nursing research can improve the depth and breadth of every nurse's professional practice





# Research methods: Qualitative vs quantitative

## Qualitative research

Focuses on exploring ideas and formulating a theory or hypothesis

Analysed by summarising, categorising and interpreting

Mainly expressed in words

Requires few respondents

Open-ended questions

Key terms: understanding, context, complexity, subjectivity

## Quantitative research

Focuses on testing theories and hypotheses

Analysed through statistical analysis

Mainly expressed in numbers, graphs and tables

Requires many respondents

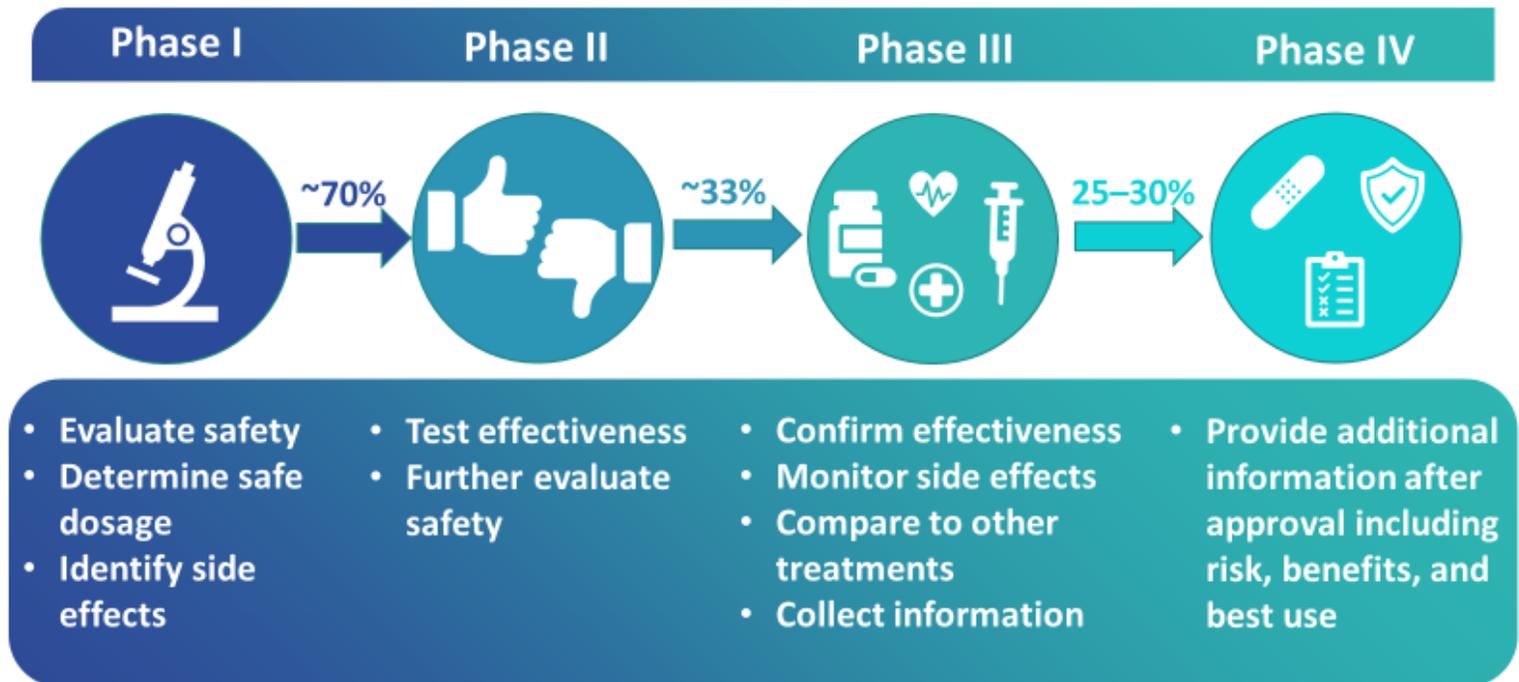
Closed (multiple choice) questions

Key terms: testing, measurement, objectivity, replicability



# Clinical research trials

- Experimental research studies aimed at evaluating a medical, surgical, or behavioural intervention
- Primary way that researchers find out if a new treatment is safe and effective
- Advance through four phases to test a treatment, find appropriate dosage, and look for side effects





# The research process

Nursing research process can be outlined using the broad steps of assessment, planning, intervention and evaluation





# Developing a strong research question

- **Focused** on a single problem or issue
- **Researchable** using primary and/or secondary sources
- **Feasible** to answer within the timeframe and practical constraints
- **Specific** enough to answer thoroughly
- **Complex** enough to develop the answer over the space of a paper or thesis
- **Relevant** to your field of study



# Incorporating research strategies into daily practice



Nurses are:

- Consumers who stay abreast of current issues and trends in MS
- Nurse champions who initiate quality improvement projects guided by the best clinical evidence
- Members of an interprofessional research team helping to address a complex health problem
- Independent nurse scientists developing a line of scientific inquiry

# Can an additional MS-Nurse supply improve adherence to therapy?



## Research example in MS-Nursing: Influence of MS-Nursing on immune-modulating treatment adherence

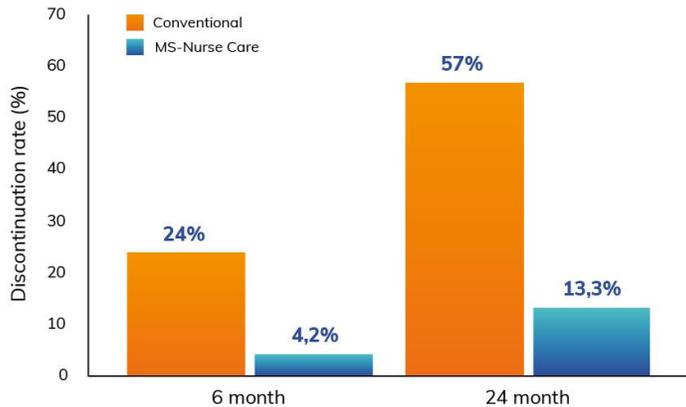


**Objectives:** Decreasing adherence to immune-modulating treatment, e.g. injectables, is an important problem that can significantly limit the efficacy of therapy



**Methods:** Open cohort study. Measurement of treatment discontinuation rates at 6 and 24 month before and after initiation of co-care by MS-Nurses

### Results:



## Real world case studies

- Course 7 contains real world case studies focused on examples of nursing research
- Example shown here highlights benefits of additional MS nursing on adherence to therapy (provided by Wolfgang Kohler)

### → Conclusions

The study provides strong evidence of substantial benefit from additional MS-Nurse care at 6 and 24 month after onset of immune-modulating therapy with injectables.



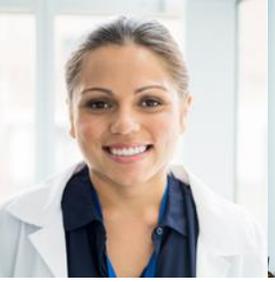
# Benefits of MS nursing research

Nursing research can offer benefits, both for people with MS and for nurses taking part in the research:

- Improves nursing activities, interventions, or approaches to enhance professional practice
- Helps improve patient outcomes
- Can help improve quality of life of nurses, along with their work environment and health
- Ensures nursing practice remains relevant and supportive

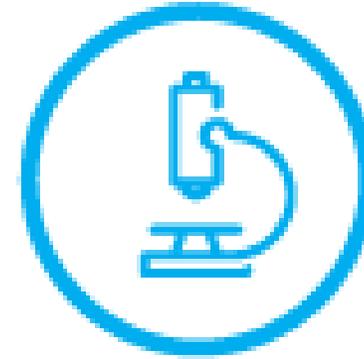
Individual benefits to nurses include:

- Gaining new skills
- Improved confidence in handling data



# Research in MS Nursing Practice

- Completely new, 5 hour, e-learning course
- Self-paced with certificate of completion
- Equips nurses to run their own research project
- Launched today!



## Research in MS Nursing Practice

From understanding the value of research to its implementing in clinical practice

# Discussion

MS **Nurse PRO** 



# Join MS Nurse PRO



Become more skilled in all aspects of multiple sclerosis nursing



Get certified and improve your curriculum



Increase your self-confidence in conversations with your patients and colleagues



Join an international community of colleagues that also care for persons with multiple sclerosis



Share your own experiences, in your own mother tongue, and ask for feedback



Share your expertise with young graduates