

DEVELOPING A PALLIATIVE CARE SERVICE FOR PATIENTS SEVERELY AFFECTED BY MULTIPLE SCLEROSIS

Dr Polly Edmonds

Consultant in Palliative Medicine

Kings College Hospital NHS Trust

50 Years
Striking
Back



King's College Hospital



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Research Question:

Can the needs of people severely affected by MS be met by a Palliative Care Service?

3 year research project funded by MS Society:

- Service modelling study
- Development of a new clinical service
- **Evaluation of the service**



Population

- Proportion of people severely affected by MS unknown
- Definition of advanced disease can be subjective
- EDSS > 8 used as a reference point for this study
 - At this level patients are unable to walk or transfer and have limited upper limb and/ or bulbar function
 - Referrals taken on basis of need rather than function



Aims

Primary aim:

- To determine whether a new neurology and palliative care service for people with severe multiple sclerosis (MS) improved outcomes for people affected by MS (PwMS)

Secondary aims:

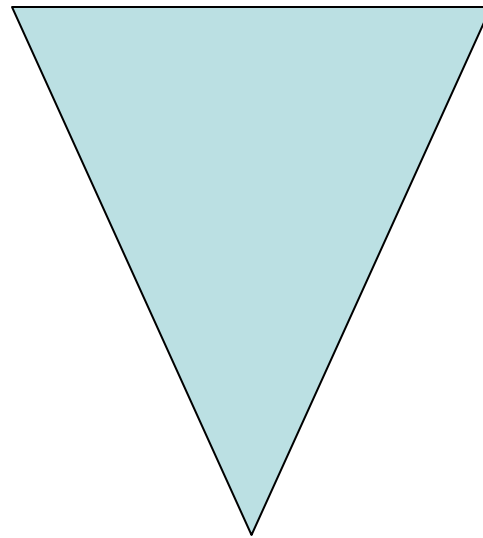
- To describe the nature of PwMS referred to the service and their symptoms and problems
- To determine whether there were any changes over time in symptom control, psychosocial concerns, information provision and services received



The Structure of the Service

Direct patient
care

Education



Information-Service mapping

Mapping

- S E London Strategic Health Authority area mapped
- COMPASS
- Produced book and website



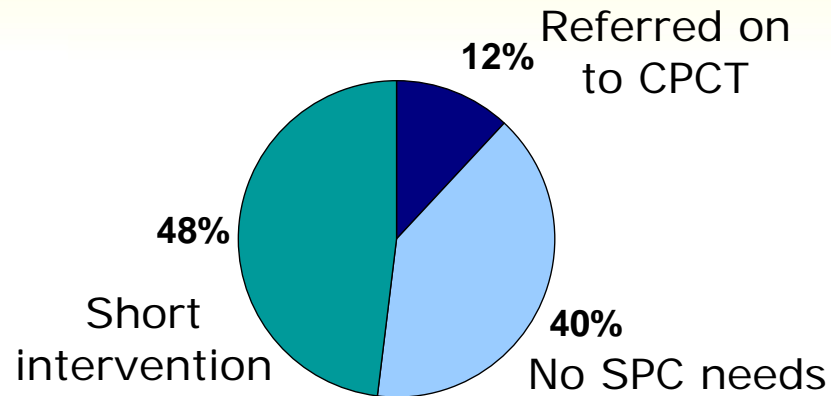
Education

- Palliative Care for people with MS education programme
 - 9 sessions
 - 234 participants
 - 77% quite or very useful

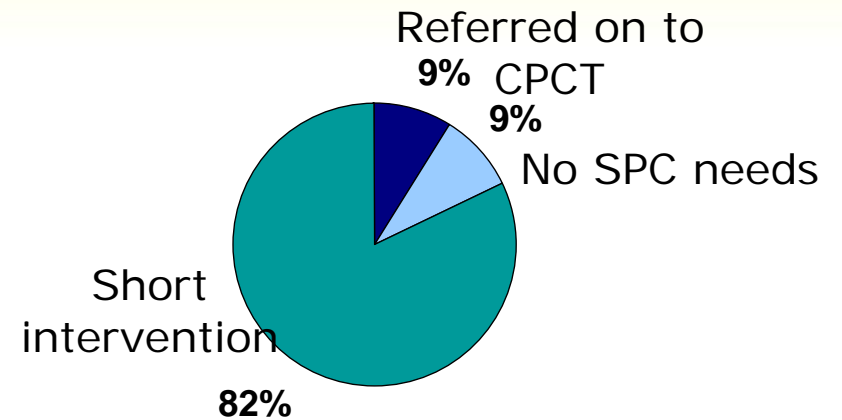


Characteristics of referrals

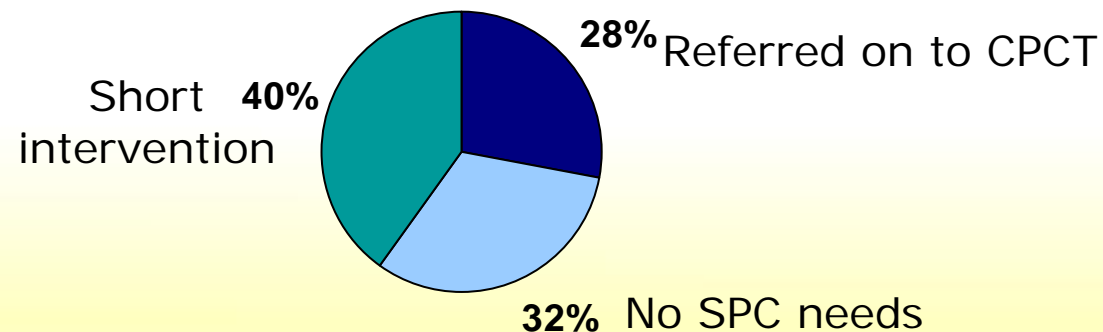
ON STUDY (n=52)



OFF STUDY (n=17)



PRE STUDY (n=25)



Evaluation of Clinical Service



Methods

- Randomised controlled trial
 - **Fast track intervention group (FI)** – palliative care service offered immediately
 - **Standard intervention group (SI)** - seen after 3 months
- Data collected at baseline (I1), 4-6 weeks (I2), 12 weeks (I3), 16-18 weeks (I4), 24 weeks (I5)
- Face to face interviews collecting demographic and clinical details, standard quality of life questionnaires



Questionnaires

- **UNDS** (United Kingdom Neurological Disability Scale)
 - 12 sections designed to assess disability in PWMS
- **EDSS** (Expanded Disability Status Scale)
 - 10-point rating scale used to identify level of MS disability
- **MSIS** (Multiple Sclerosis Impact Scale)
 - 29 questions on a variety of MS-related symptoms on a 1-5 scale
- **POS** (Palliative Care Outcome Scale) + **POS-MS symptoms**
 - 10 items on anxiety, patient and carer concerns, practical needs
 - 18 questions specifically relating to MS symptoms on a 0-4 scale
- **Structured** health / social services / demographic **interview**
 - Record of frequency and types of health / social services received
 - Basic demographic information collected
- **AMTS** (Abbreviated Mental Test Score)
 - 10 simple questions used to assess cognitive function



Analysis

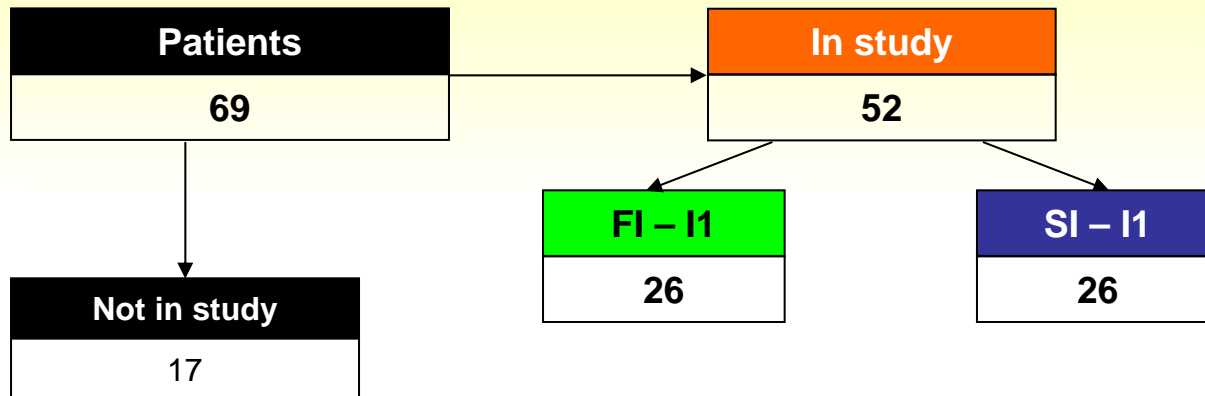
- Comparison of FI and SI at baseline (I1)
- Description of problems and symptoms
- Comparison FI and SI at:
 - 4-6 weeks after baseline (I2)
 - 3 months after baseline (I3)
- $P < 0.05$ taken as statistically significant



Findings



PwMS included



Demographics (1)

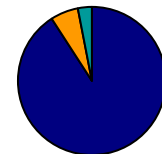
- N=52 PwMS randomised to study
- Basic descriptive demographics:

• Age **53** (av.); range 33-75; st dev 10.4

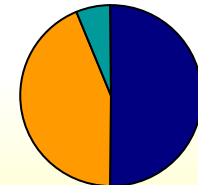
• Gender **69% Female**
31% Male



• Ethnicity **91% White**
6% Black
3% Other



• Type of MS **50% Secondary progressive**
44% Primary progressive
6% Other (RRMS, Devic's, MSA)



Demographics (2)

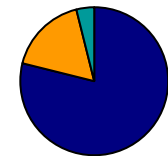
- Further descriptive demographics:

- Date diagnosis **1987** (av.); range 1950-2005; st dev 9.6

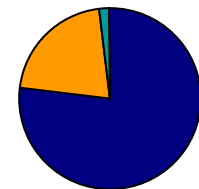
- Informal carer **83%** Have an informal carer
17% No informal carer



- Living status **79%** Live with carer (informal/formal)
17% Live alone
4% Live in care / nursing home



- Employment status **77%** Unable to work (due to MS)
21% Retired
2% In employment

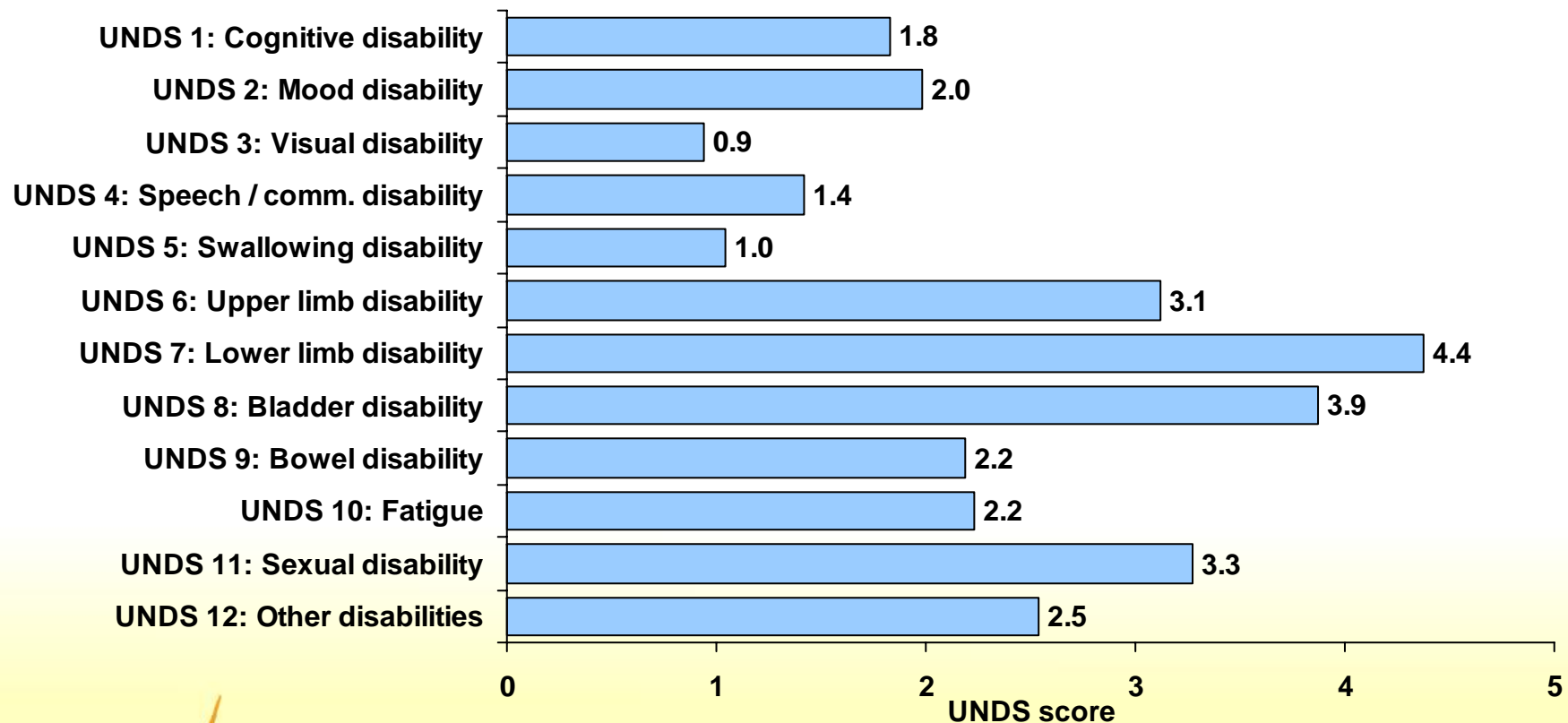


No difference between **FI** and **SI** groups (baseline)



Level of disability

- Average EDSS score: **7.8**
- Average total UNDS score: **28.8** (sum 12 items – shown individually):



Symptom profile of PwMS



Symptom burden

- POS-MS-S1 was used to discuss 18 common symptoms
 - PwMS reported suffering from **nine** symptoms on average
 - **Six** of these nine rated as affecting PwMS “moderately” to “overwhelmingly”
 - **Three** of these nine rated as affecting PwMS “severely” or worse

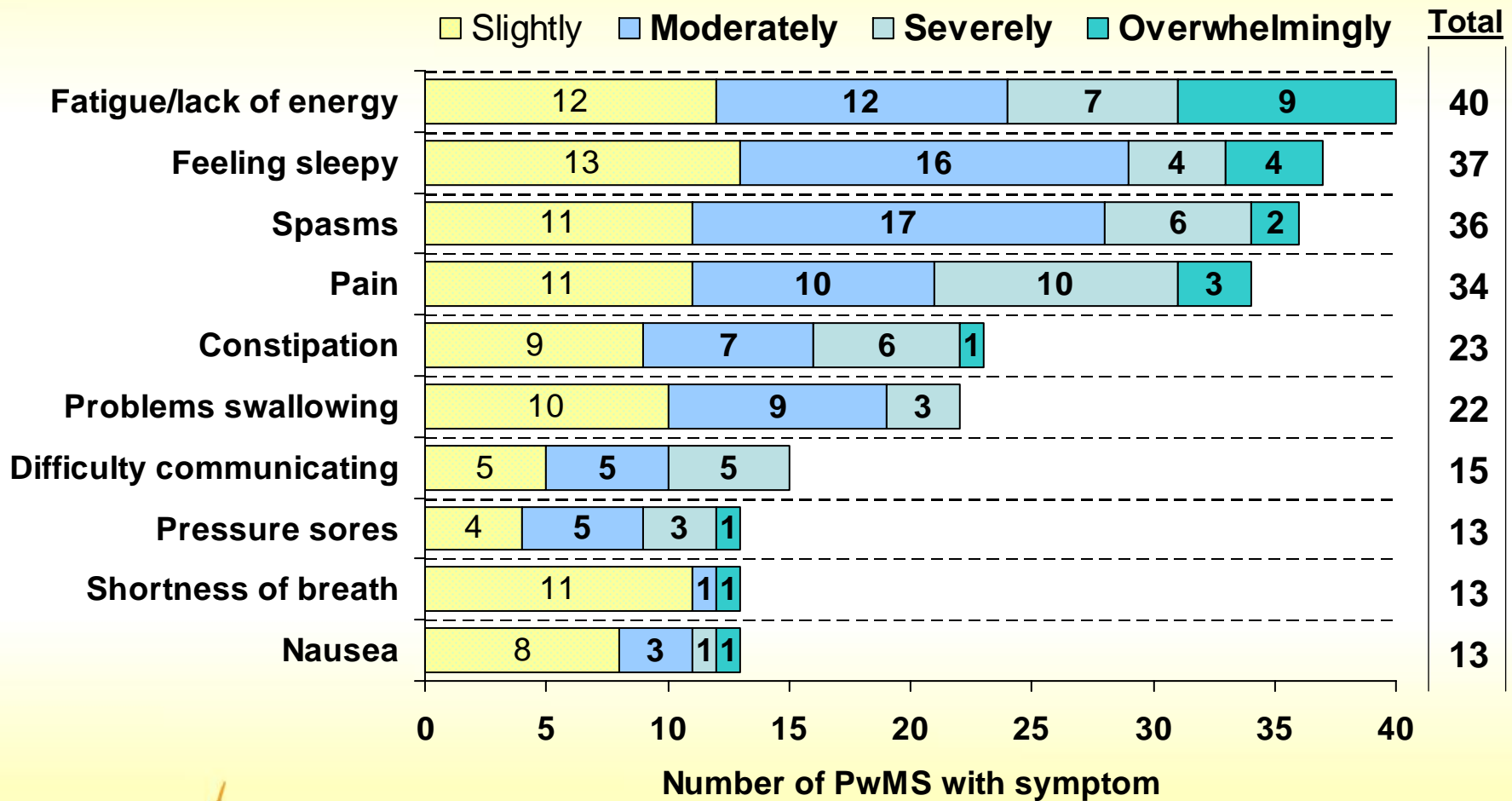
- Symptoms most often mentioned were:

- Problems using legs* (44 PwMS)
- Fatigue / lack of energy* (40 PwMS)
- Problems using arms (39 PwMS)
- Feeling sleepy (37 PwMS)
- Spasms (36 PwMS)
- Pain* (34 PwMS)

* Symptom affected PwMS severely or worse

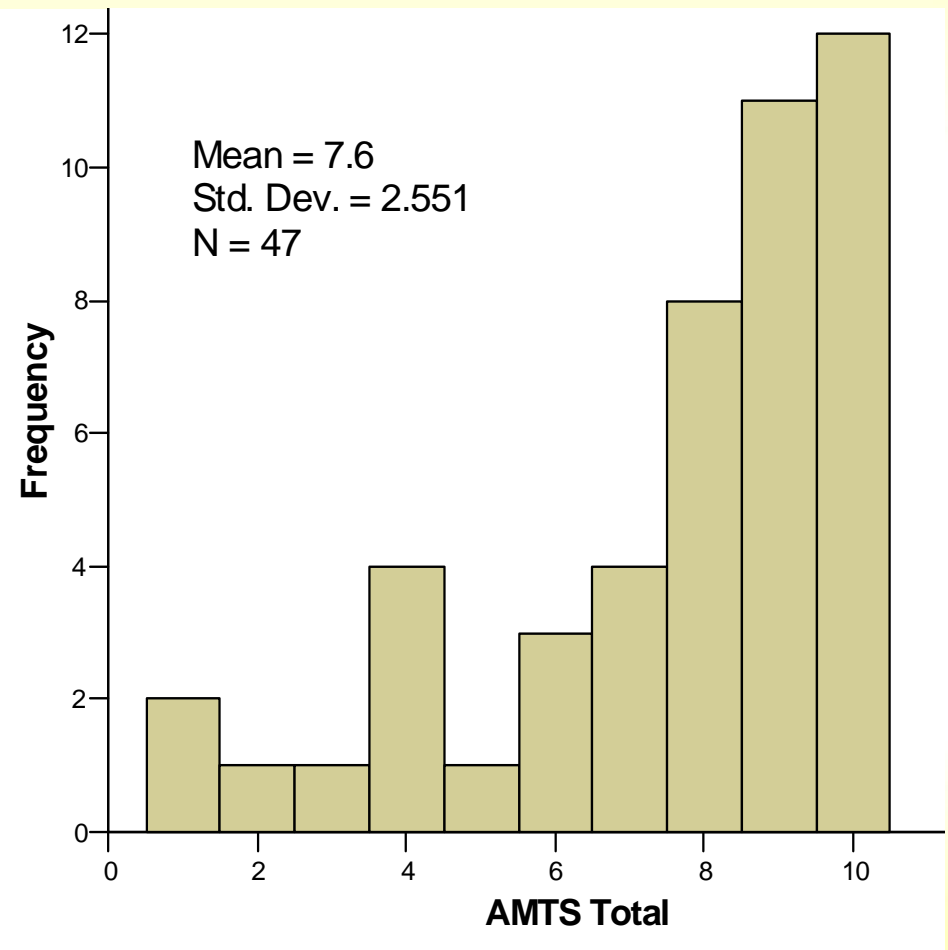


Symptom burden (n=52)



Cognitive problems

- A quarter (12 PwMS) scored 6 out of 10 or lower on the Abbreviated Mental Test Score (AMTS)
 - Most commonly correct:
 - Present Monarch (94% correct)
 - Orientation (92% correct)
 - Most commonly wrong:
 - Start WWI (only 45% correct)
 - Memory recall (55% correct)



Comparison with other advanced diseases

Symptom	MS ¹	Cancer ²	Heart disease ²	Respiratory disease ²
Pain	68%	35-96%	41-77%	34-77%
Fatigue	80%	32-90%	69-82%	68-80%
Nausea	26%	6-68%	17-48%	?
Constipation	47%	23-65%	38-42%	27-44%
Breathlessness	26%	10-70%	60-88%	90-95%

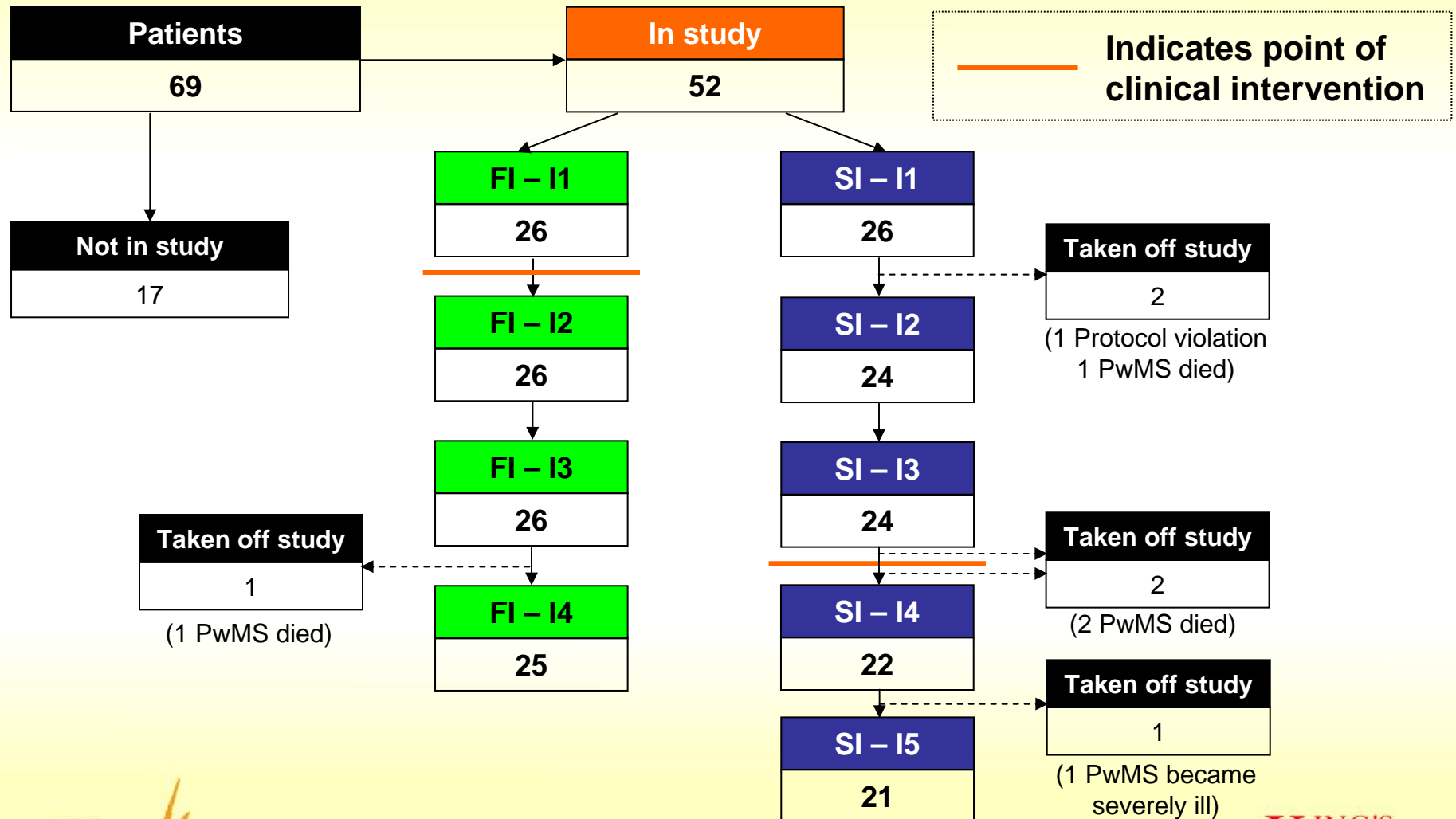
¹ King's study - % with symptom

² Solano, Gomes, Higginson. Journal of Pain and Symptom Management, 2006: 31:58-69.

Comparison of FI and SI groups over time



PwMS included



Differences at 4-6 weeks (I2)

- PwMS in FI group had small but significant improvement in nausea compared to SI group ($p=0.039$)
 - PwMS with nausea: **FI 1, SI 6**
- PwMS in FI group more likely to have seen a paid carer more recently than in SI group ($p=0.018$)
 - Last saw paid carer: **FI 0 days ago, SI 3.9 days ago (1 outlier)**



Differences at 12 weeks (I3)

- Improvement in nausea maintained among PwMS in FI group
- Informal carers of PwMS in FI group reported:
 - Lower suffering of health (p=0.018)
 - I1: **FI** mean 1.15; **SI** mean 1.63
 - I3: **FI** mean 0.56; **SI** mean 1.67
 - Less loss of control over life (p=0.020)
 - I1: **FI** mean 1.54; **SI** mean 1.84
 - I3: **FI** mean 1.06; **SI** mean 2.00
 - More informal carers reported that they had learned new skills (p=0.005)
 - Learned new skills caring for relative: **FI** 15; **SI** 7



Summary

- Many PwMS have a large symptom burden and face challenges of severe disability
 - Fatigue, pain and spasms are particularly prevalent
 - Symptom burden is at least as severe as other groups of patients with advanced disease
- The palliative care service for PwMS improved nausea and informal carer wellbeing
 - Effect strongest after initial palliative care contact

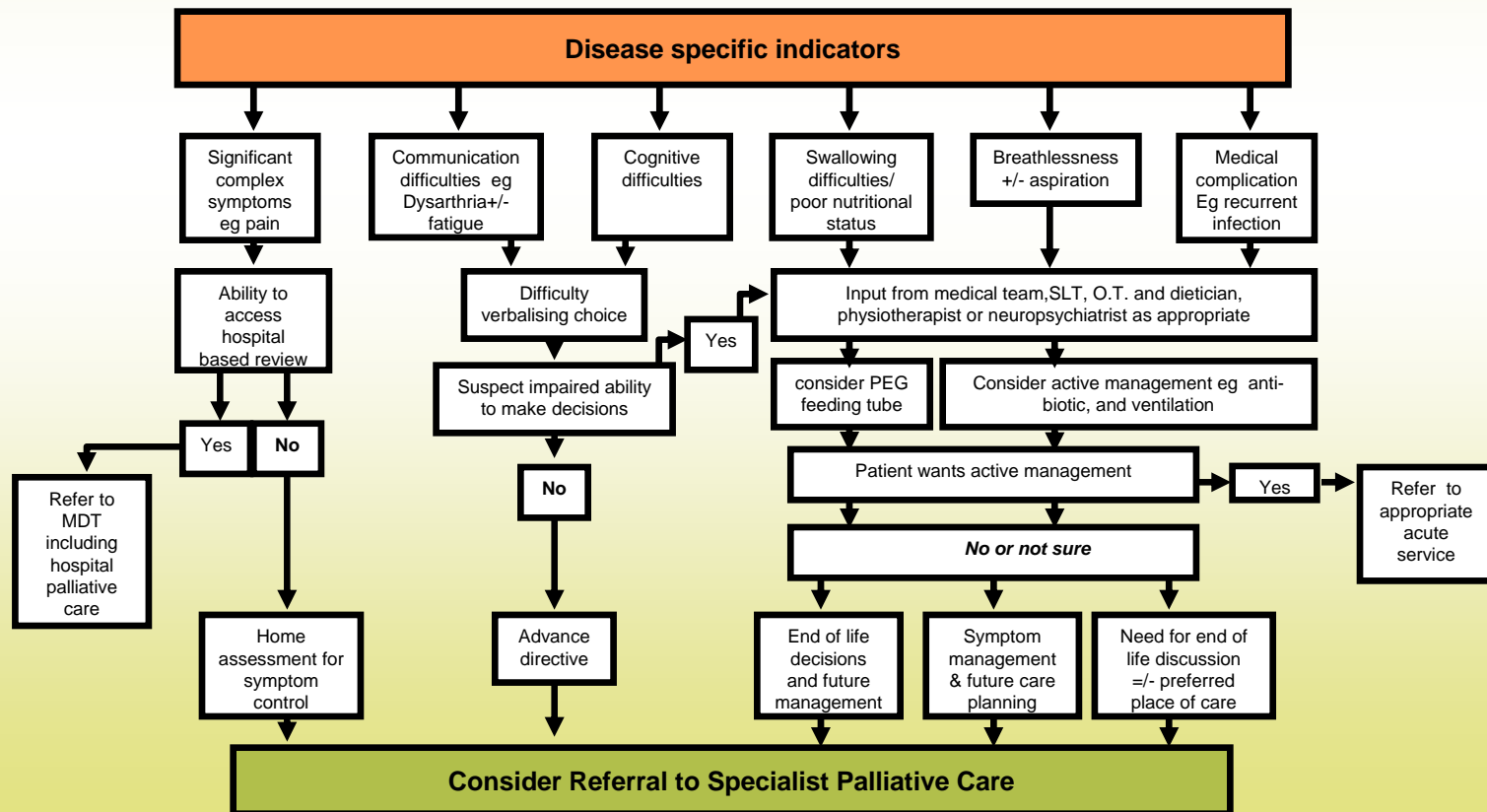


Pathway for Referral of Person Severely Affected by MS To Specialist Palliative Care

- Core Indicators**
- Recent, significant functional decline (loss of ADLs)
 - Dependence in 3 ADLs or more
 - Multiple co-morbidities
 - Weight loss
 - Serum albumin <25
 - Karnofsky score <50%
 - Severe progression of disease over recent months
 - Recent increase in infective episodes requiring hospitalisation

Consider holistic assessment using palliative care approach having regard to

- Quality of life
- Comfort
- Patient Choice



Information and Education Outputs

- **Referral Pathway**
- **Service directory:** <http://www.selmss.org.uk>
- **Resources**
 - Resource pack
 - MS Essentials
 - Greenwich & Bexley Neurodegenerative Special Interest Group



Southeast London MS Support Directory

<http://www.selmss.org.uk>

SELMSS Directory

ABOUT SELMSS

THE DIRECTORY

search alphabetically

search by borough

search by keyword

Welcome to the South East London Multiple Sclerosis support directory.

There are currently 338 organisations listed.

You can find the service you need in a number of different ways:

- Use an alphabetical list of services
- Find services in each borough
- Search by a list of categories

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50 Years
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What next?

- **Research**

- Models of care
- Specific symptom management
- Evidence based management guidelines for care of PwMS

- **Education**

- Training to explore advanced planning & end of life care
- Training for MS Teams to support comprehensive assessment of PwMS to best identify those that would benefit from referral to specialist palliative care services

