

2023



PRIME PARKINSON

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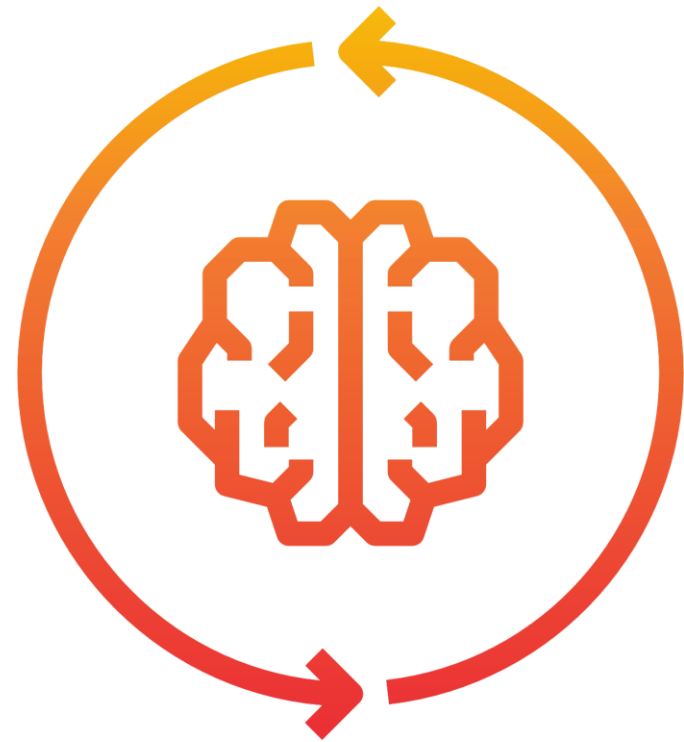
University of Bristol

Dr Katie Lloyd

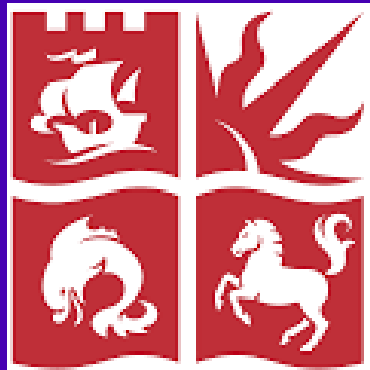
Clinical Research Fellow

University of Bristol

www.primeparkinson.blogs.bristol.ac.uk



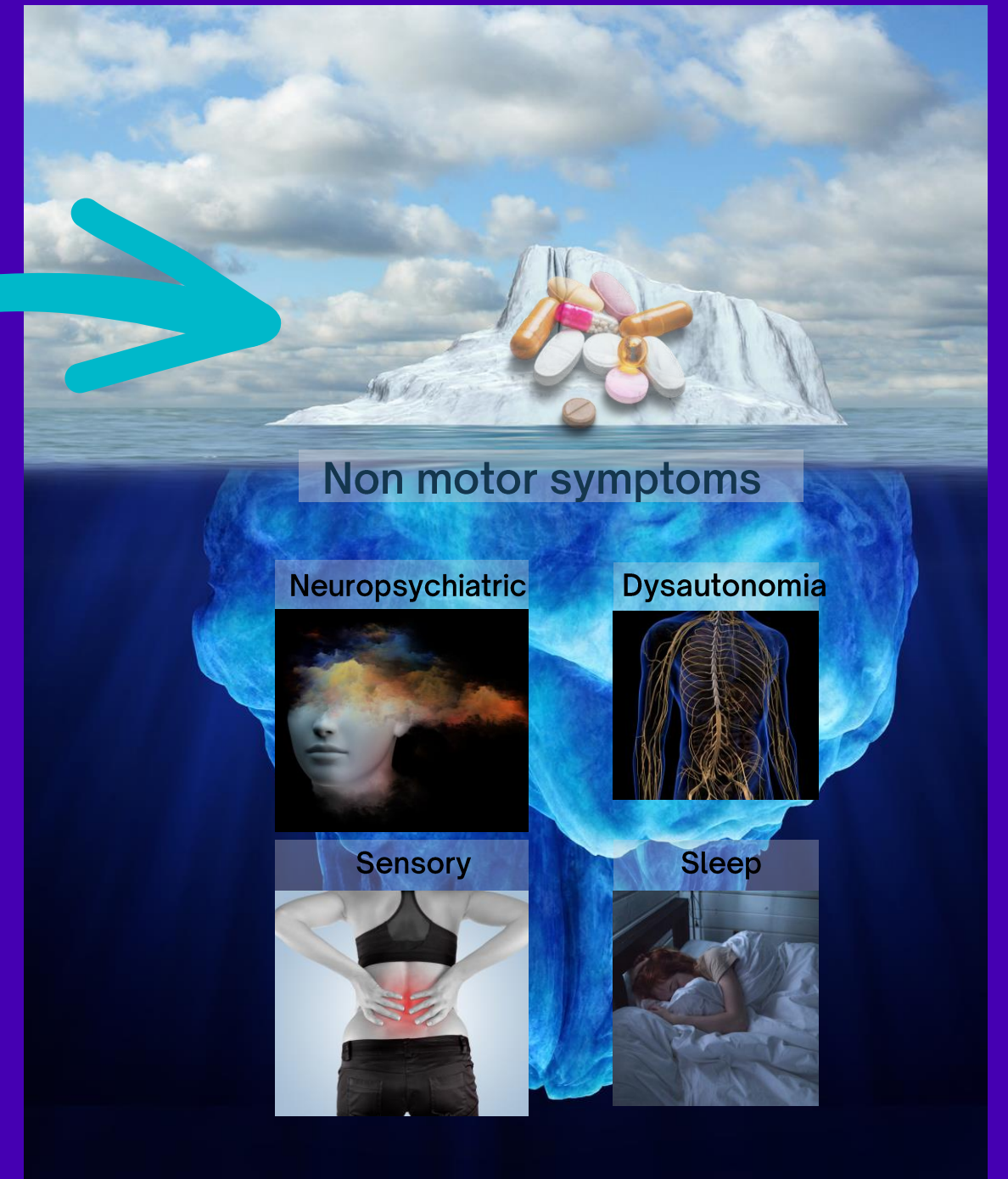
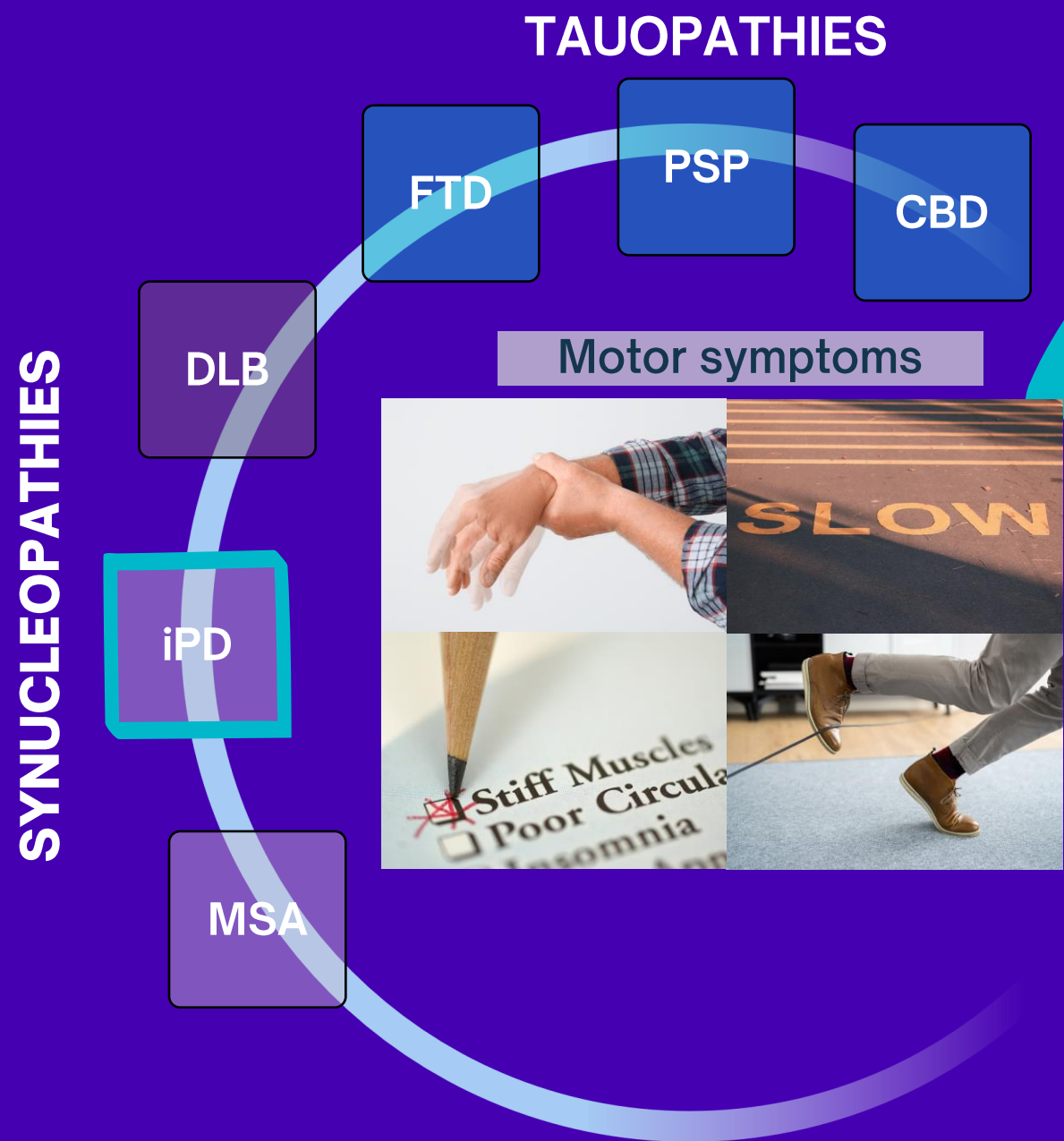
AGEING AND MOVEMENT
RESEARCH GROUP



University of
BRISTOL



Parkinson's



Current care

Not individualised

Fragmented &
silo'ed

Under-represents the
population

Disempowers PwP

Reactive

Fails to recognise
important symptoms



“Who is at risk”?

PRIME-EPI



Male					Female						
Age	CMS ↓	Parkinsonism duration →	<2yr	2-4yr	5+yr	Age	CMS ↓	Parkinsonism duration →	<2yr	2-4yr	5+yr
35-64	0/1		7%	10%	14%	35-64	0/1		8%	11%	15%
	2/3		10%	14%	19%		2/3		11%	16%	20%
	4+		15%	20%	24%		4+		16%	22%	26%
65-70	0/1		10%	13%	17%	65-70	0/1		10%	14%	18%
	2/3		14%	18%	22%		2/3		15%	19%	23%
	4+		19%	25%	29%		4+		20%	26%	30%
70-74	0/1		13%	17%	21%	70-74	0/1		13%	17%	21%
	2/3		18%	23%	27%		2/3		18%	23%	27%
	4+		25%	30%	33%		4+		25%	30%	33%
75-79	0/1		17%	21%	25%	75-79	0/1		16%	20%	24%
	2/3		23%	28%	31%		2/3		22%	27%	30%
	4+		31%	36%	39%		4+		30%	35%	38%
80-84	0/1		22%	26%	29%	80-84	0/1		20%	24%	28%
	2/3		29%	34%	36%		2/3		27%	32%	35%
	4+		38%	43%	44%		4+		35%	40%	42%
85+	0/1		28%	31%	34%	85+	0/1		25%	28%	31%
	2/3		36%	40%	42%		2/3		33%	37%	38%
	4+		45%	49%	50%		4+		41%	46%	46%

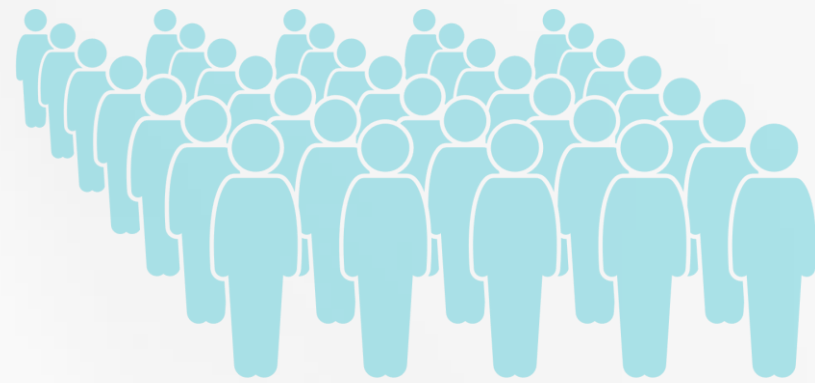
CMS: Cambridge Multimorbidity Score
 Annual risk 0- 15%
 Annual risk 16- 30%
 Annual risk >30%



REI'MAGINE HEALTHCARE TOGETHER

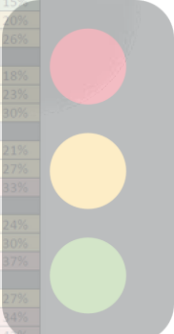
“Who is at risk”?

PRIME-EPI



Male				Female			
Age	CMS ↓	Parkinsonism duration →		Age	CMS ↓	Parkinsonism duration →	
35-64	0/1	<2yr	7%	35-64	0/1	<2yr	8%
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	4+	5+yr	14%		4+	5+yr	15%
65-70	0/1	<2yr	10%	65-70	0/1	<2yr	10%
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75-79	0/1	<2yr	17%	75-79	0/1	<2yr	16%
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85+	0/1	<2yr	28%	85+	0/1	<2yr	25%
	2/3	2-4yr	31%		2/3	2-4yr	28%
	4+	5+yr	34%		4+	5+yr	31%

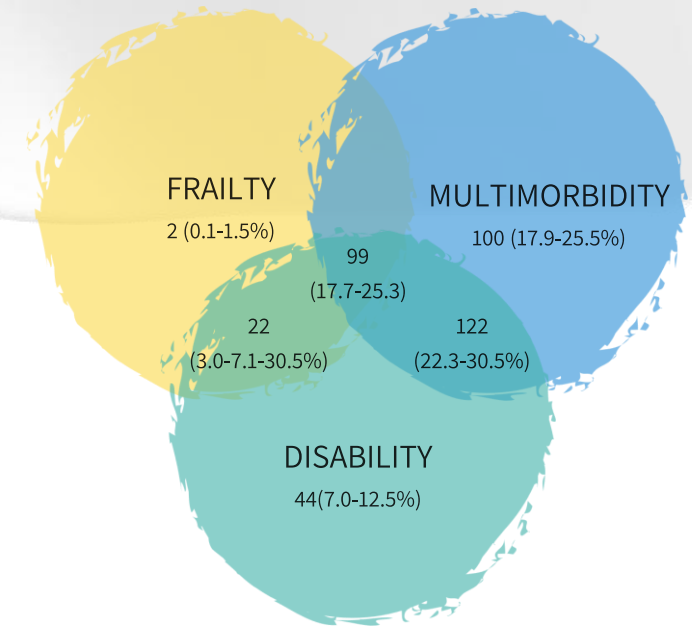
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REI'MAGINE HEALTHCARE TOGETHER

“Who are we trying to reach?”

PRIME-XS



PRIME-EPI



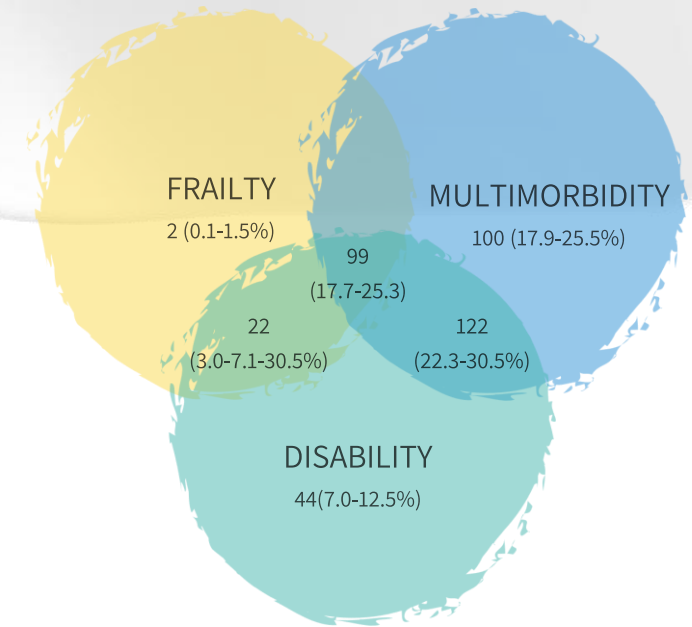
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85+	0/1		28%	31%	34%	85+	0/1		25%	28%	31%
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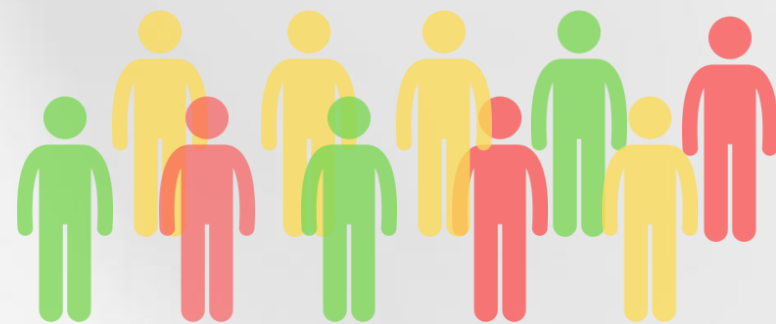


REIMAGINE HEALTHCARE TOGETHER

PRIME-XS



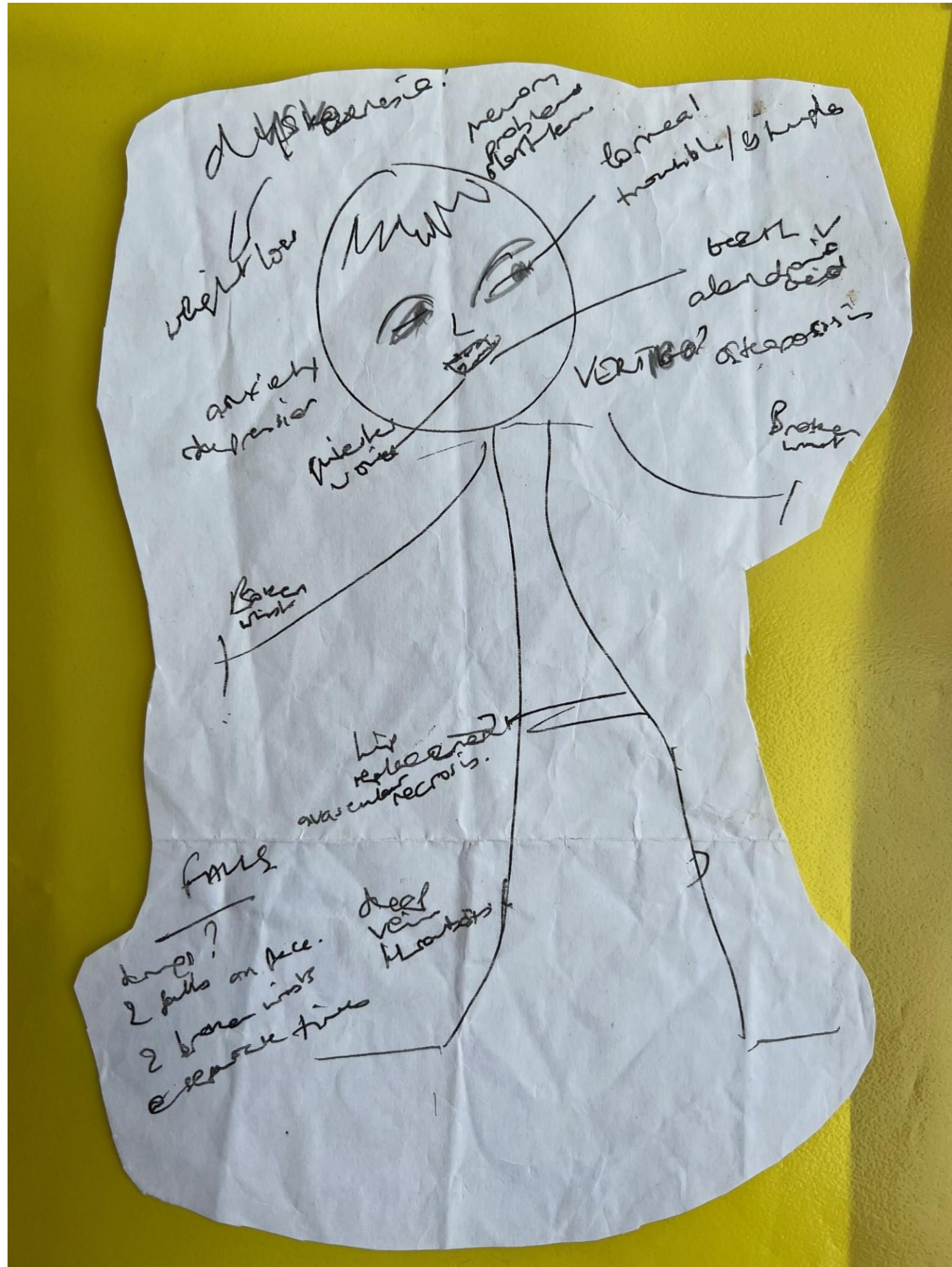
PRIME-RCT





This call means the world to me. I used to lie on my sofa crying as I couldn't get help from anyone.





Shared with permission

- 72yo retired music teacher
- PD for last 17 years
- “Advanced disease”
 - Walking with frame
 - Apomorphine pump
 - Cognitive impairment
 - Hallucinations
 - Dysphagia
- Medications felt to be optimised
- Ongoing significant symptom burden

Thinking about the future

I can think about the future without any concern

I can think about the future with only a little concern

I can only think about the future with some concern

I can only think about the future with a lot of concern

reset



A high palliative care need population

Lack of to effective palliative

- Poor knowledge of palliative care services available
- Lack of preparation for death
- Carers report difficulty initiating discussions
- Less likely to seek help for SPC or hospice

Have you ever had thoughts about end-of-life plans?

When do you think it is the best time to bring up end-of-life decisions?	Percentage	Count (N)
Before getting sick, while healthy	80%	72
When first diagnosed with a life-threatening or progressive illness	12%	11
When first sick with a life-threatening or progressive illness	2%	2
When first hospitalized with a life-threatening or progressive illness	3%	3
If dying	2%	2

43% (N = 38)

1% (N = 1)

3% (N = 2)

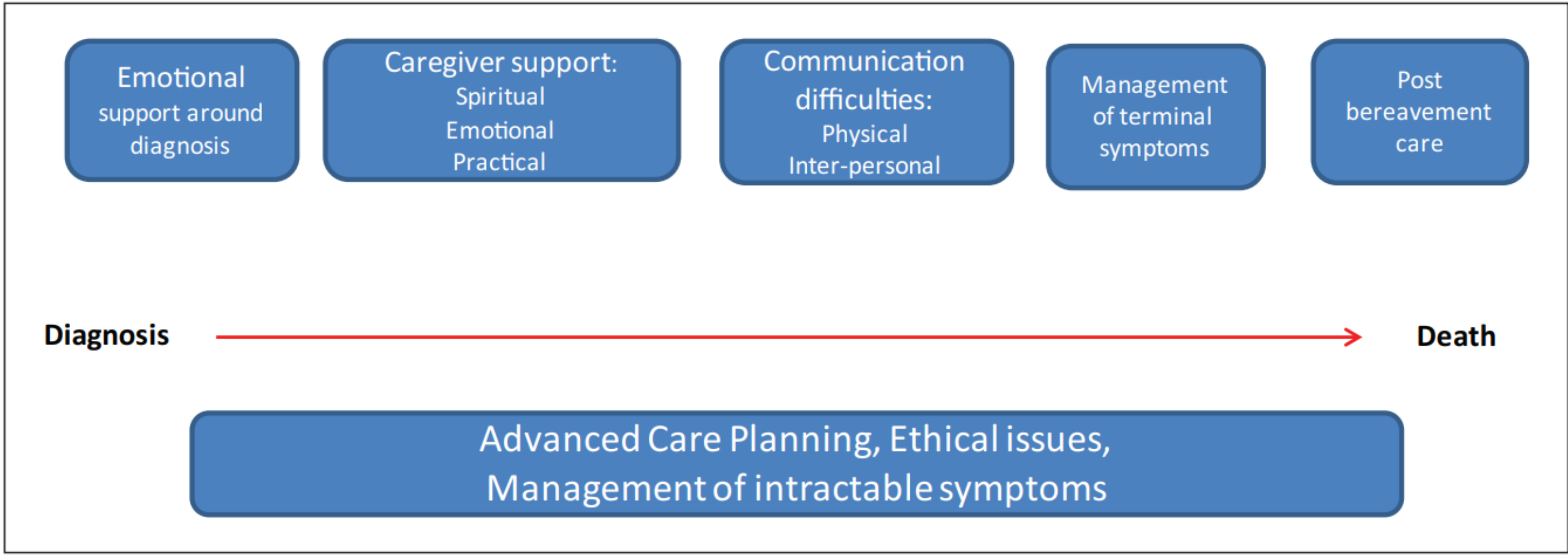
0% (N = 0)

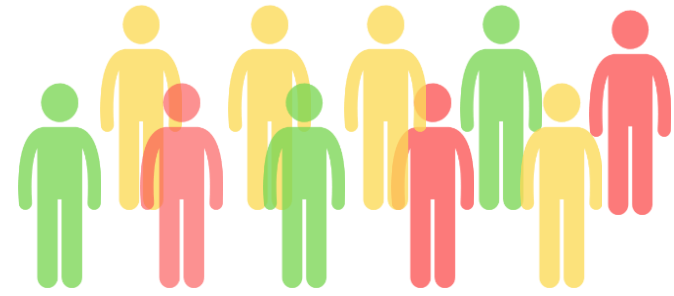
48% (N = 43)

6% (N = 5)

Features

- Depression, anxiety, communicating with family
- Unable to make decisions about care in last 6 months
- Disability in disease course





POS-S PD
ICECAP-O 2



Individual clinic review of
palliative care needs

REIMAGINE HEALTHCARE TOGETHER

ICECAP-O 2 - Future	Freq.	Percent	Cum.
Without concern	16	9.41	9.41
Little Concern	61	35.88	45.29
Some Concern	67	39.41	84.71
Alot of Concern	26	15.29	100.00
Total	170	100.00	

PRI'ME 
PARKINSON

REI'MAGINE
HEALTHCARE
TOGETHER

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