



UNIVERSITY OF
LIVERPOOL

The Walton Centre



NHS Foundation Trust

Excellence in Neuroscience



Epilepsy, co-morbidities and Quality of Life

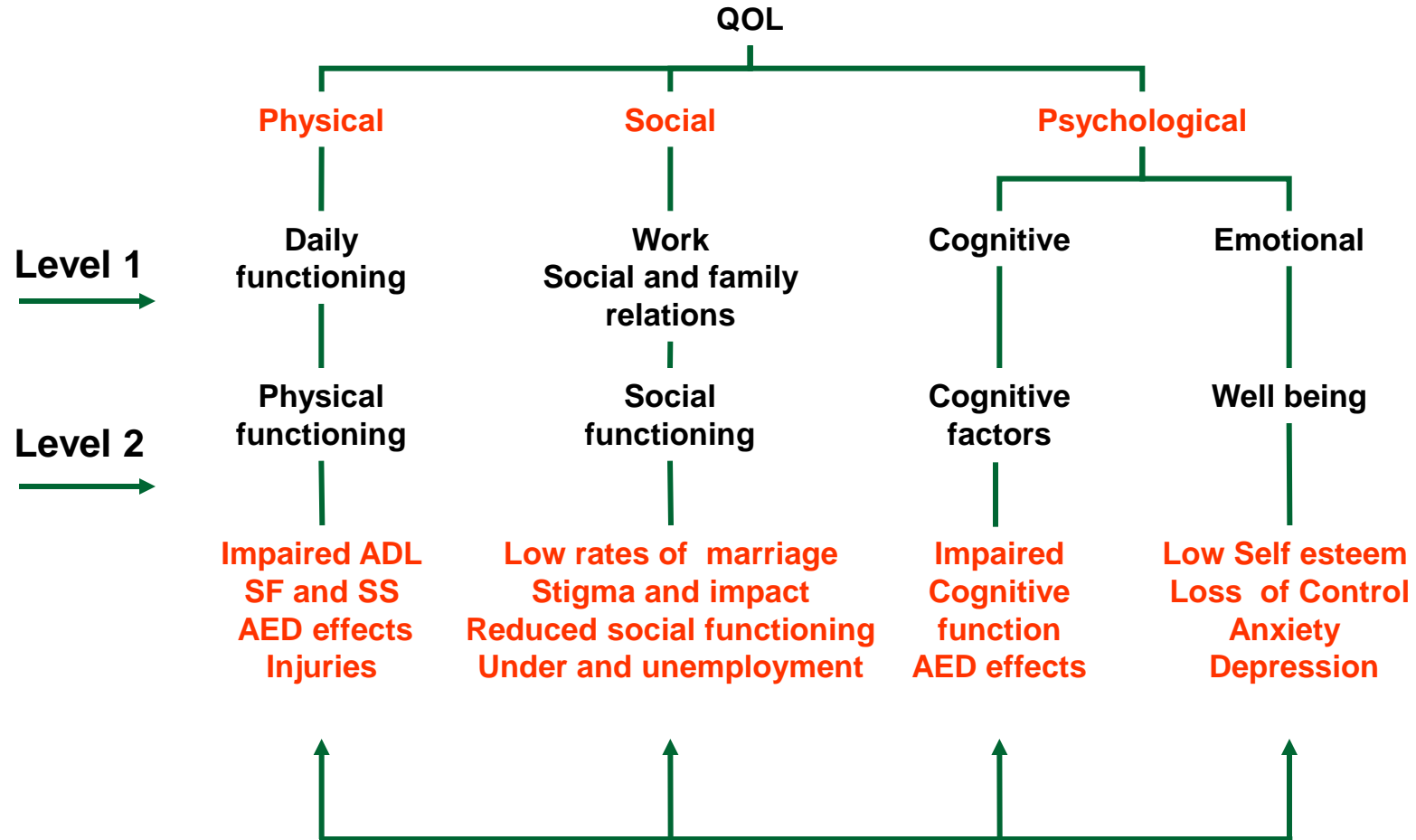


Professor Gus A Baker PhD FBPS

Aims of Presentation

- What is Quality of life [QOL]?
 - What do we know about the impact of epilepsy on QOL ?
 - What are the co-morbidities of epilepsy?
 - What do we know about the impact of epilepsy plus co-morbidities on QOL?
 - What research questions are generated in respect of the above?
-

Interactions between epilepsy co-morbidities and QOL



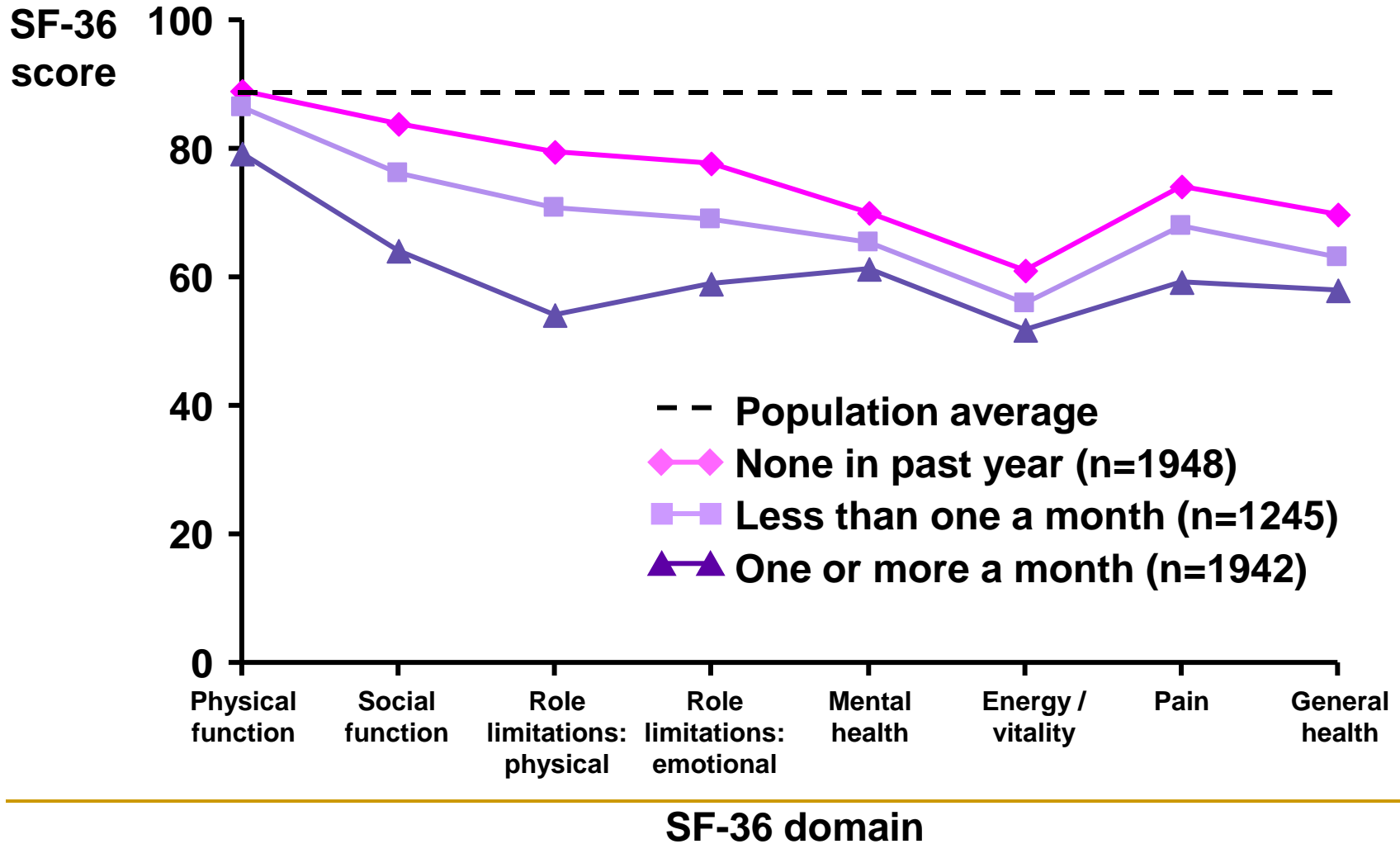
Definition of QOL

- Quality of life is defined as individuals' perceptions of their position in life in the context of the culture and value systems in which they live and in relation to their goals, expectations, standards and concerns” The term “health-related quality of life” is generally used when referring to quality of life in the context of a person's health status.
 - Relationship between QOL and Health status [often used interchangeably]
 - QOL is multidimensional
-

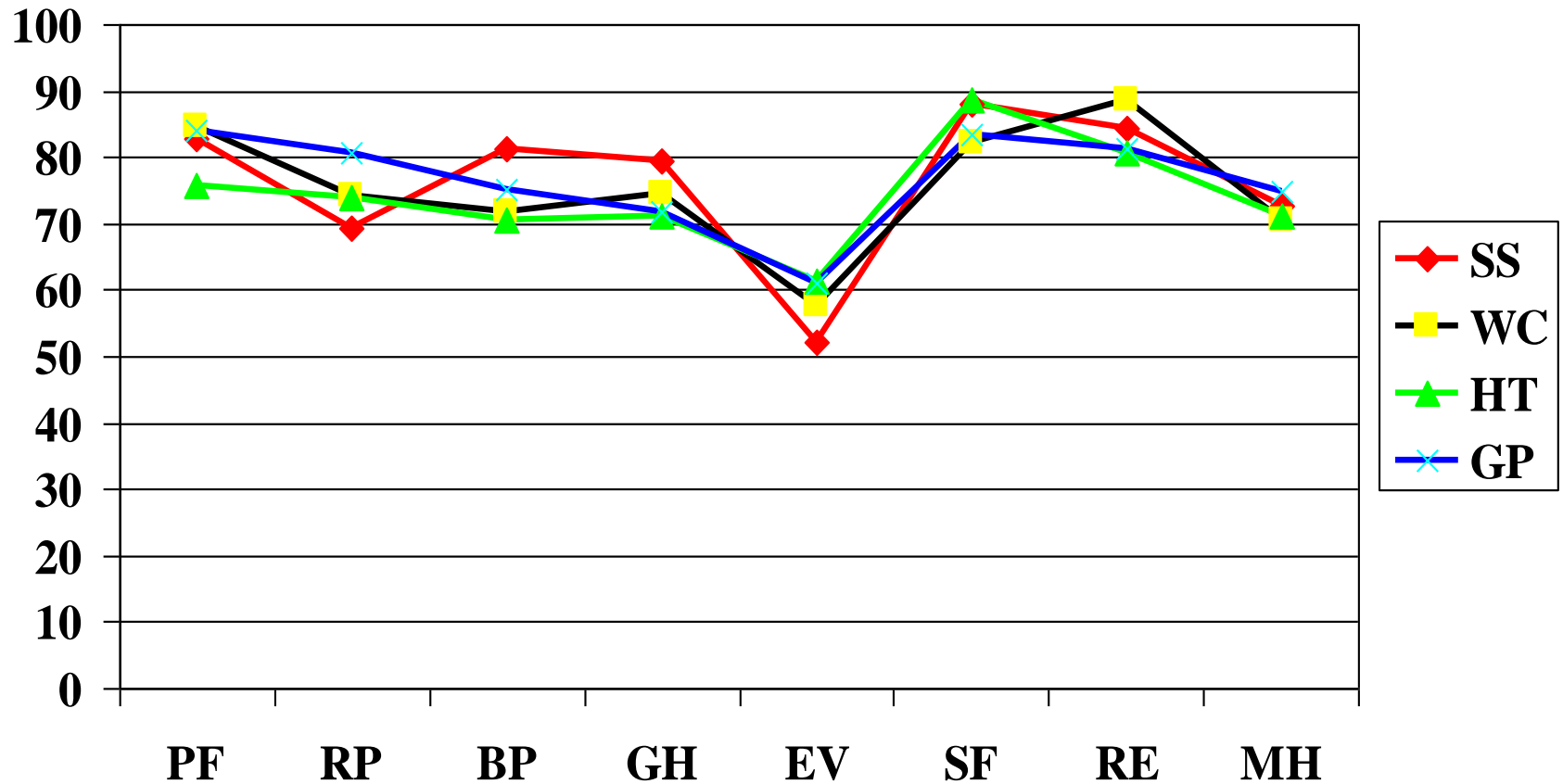
Role of Epilepsy for QOL

- A clear relationship of QOL to Seizure Frequency
 - Other weaker associations include:
 - Seizure type/combination
 - Seizure severity
 - Age of onset
 - Duration
 - AED effects
-

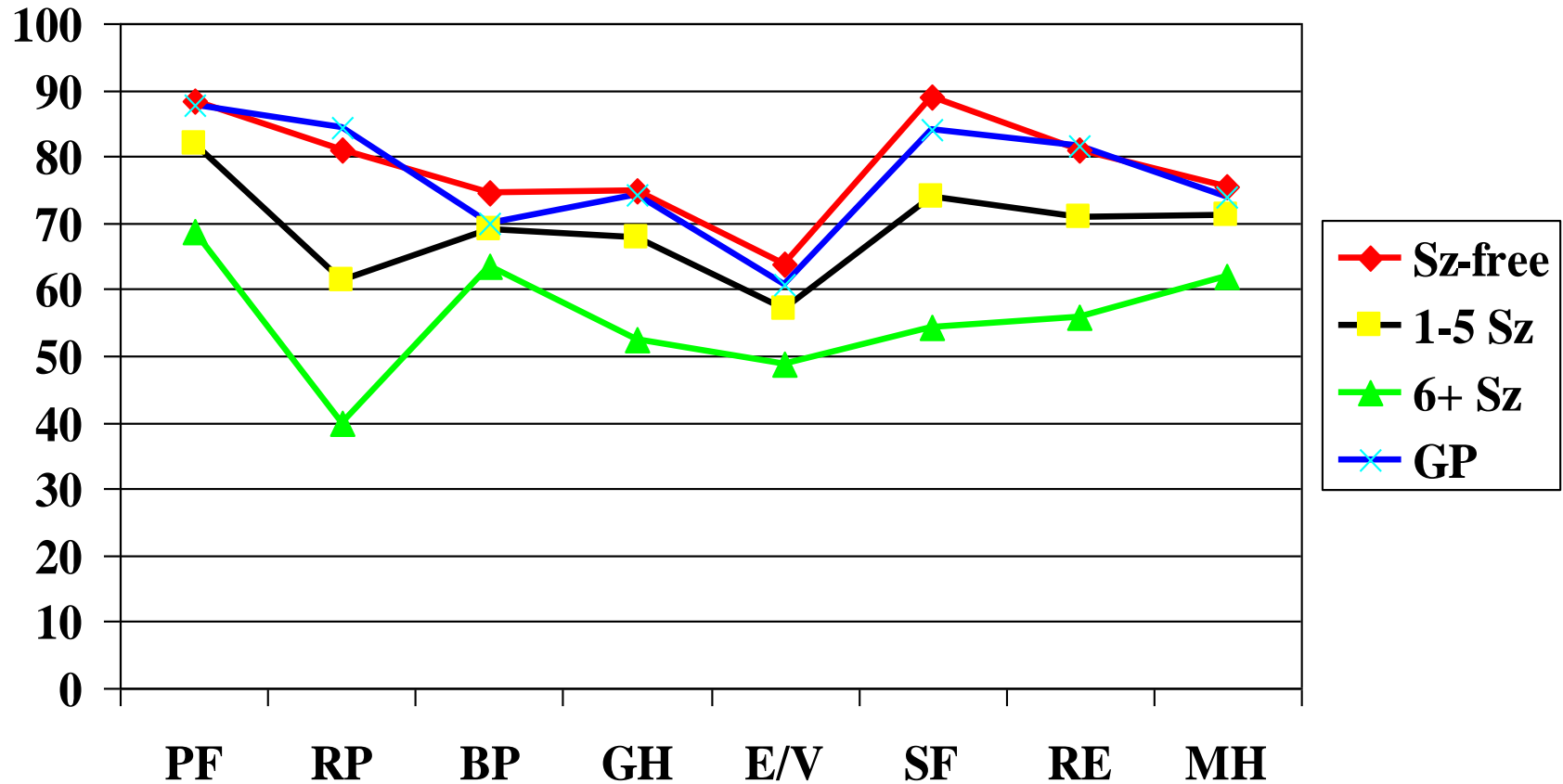
QOL by seizure frequency



Impact of Single Seizure on QOL



Role of recent seizure frequency



Perceived impact of uncontrolled seizures

Seizure activity:

None in last year

1+ per month

Impacts a lot/some on:

Relationship with family

13%

37%

Social activities

18%

55%

Ability to work

18%

45%

Overall health

21%

60%

Relationship with friends

11%

41%

Feelings of self

25%

55%

Plans for the future

24%

56%

Standard of living

16%

49%

QOL profile by epilepsy status

	Yrs since last Sz:			
	0-1	2-4	5-9	≥10
% Anxious	36	14	14	10
% Depressed	14	4	3	4
% Stigmatised	50	26	32	17
% Married	60	67	63	80
% Employed	34	48	70	68

Intractability, seizure freedom and QOL

	↓ SF of:				
	100%	75-99%	50-74%	0-50%	P value
QOLIE-89	7.32	0.96	-0.20	-0.62	0.0004
QOLIE-89 MH	6.41	1.71	-2.09	-0.52	0.0003
QOLIE-89 PH	7.11	-0.67	-0.37	-1.07	0.002
QOLIE-89 CF	4.29	-0.16	-0.37	-0.12	NS
QOLIE-89 EP	7.26	3.04	1.86	0.57	0.007
SF-36 MH	7.11	1.92	-3.53	-0.98	0.0008
SF-36 PF	3.66	-1.14	1.79	-0.98	NS

What are the common co-morbidities in epilepsy?

■ Psychological

- ❑ Anxiety
- ❑ Depression
- ❑ Low Self esteem
- ❑ Reduced mastery
- ❑ Felt stigma

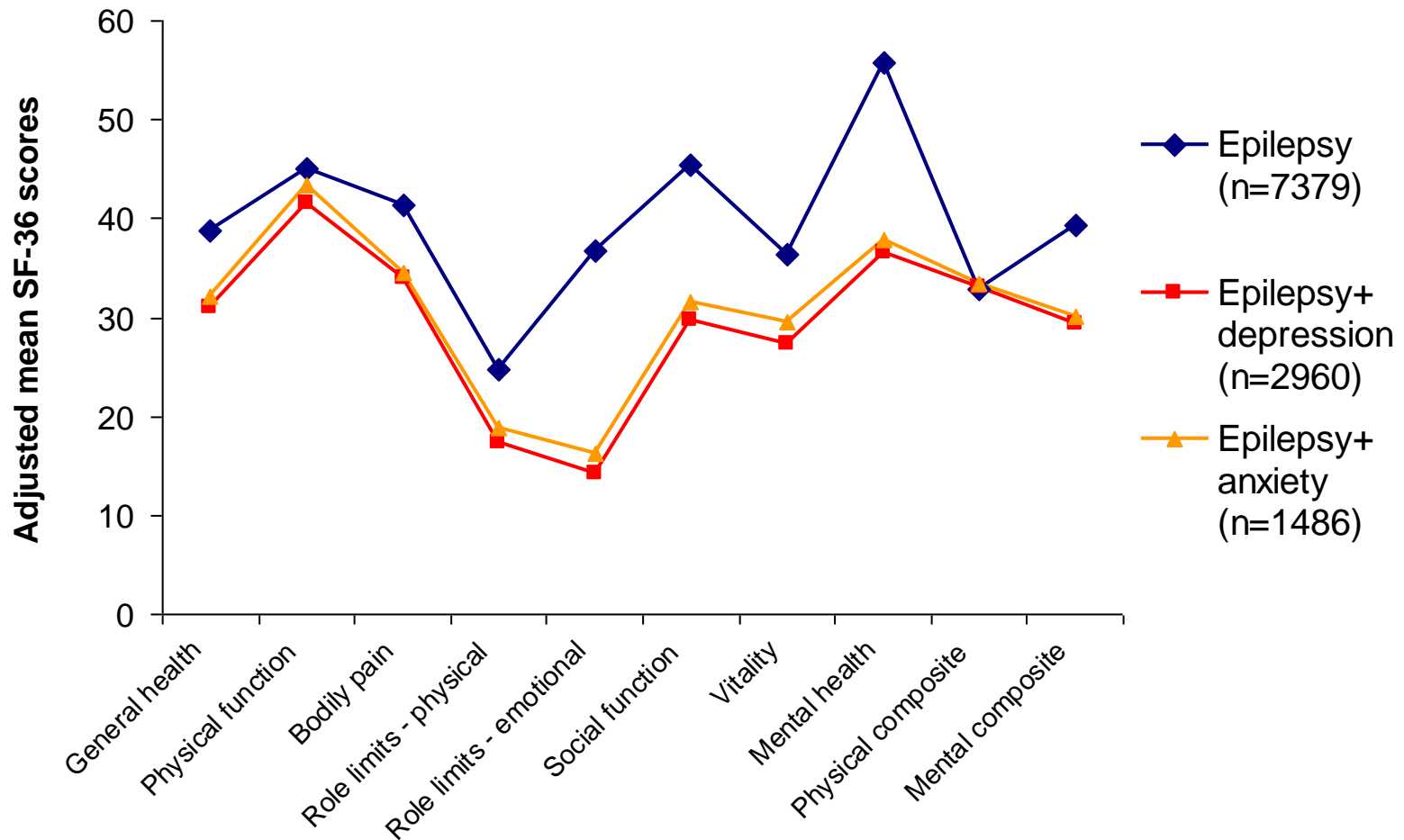
■ Neuropsychological

- ❑ Impaired memory
 - ❑ Impaired learning
 - ❑ Impaired attention and concentration
 - ❑ Impaired speed of information processing
-

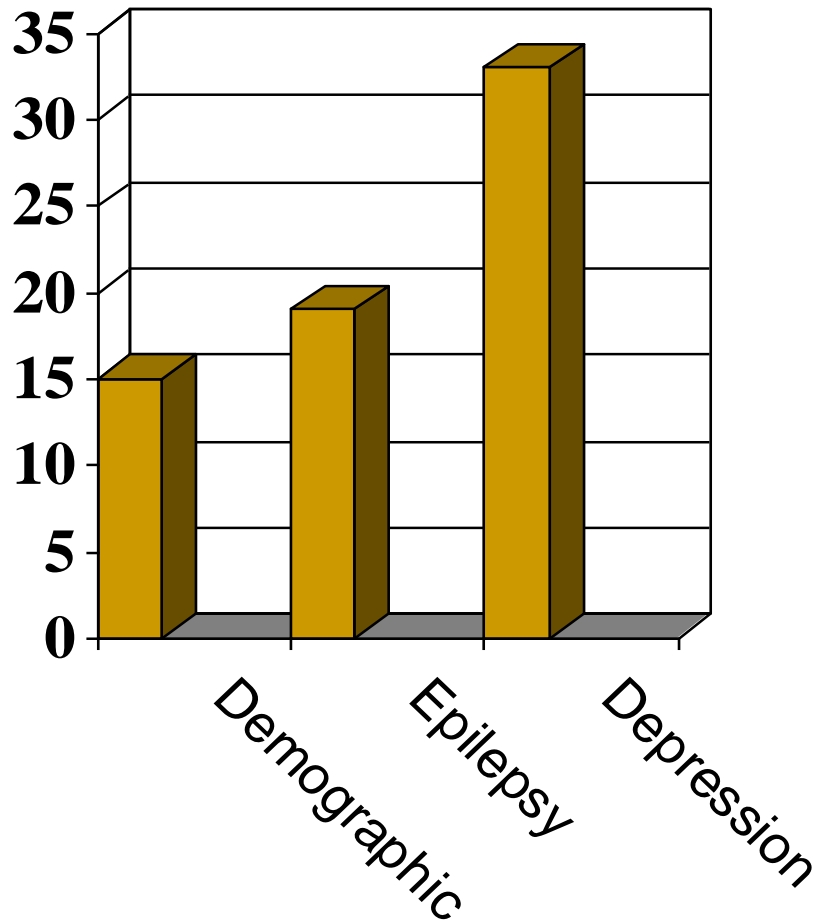
Prevalence: Community sample

		Seizure activity	
Status	None	<1 a month	1+ a month
	(n = 350) (%)	(n = 166) (%)	(n = 168) (%)
Anxiety			
Not anxious	74	53	37
Borderline	13	18	19
Case	13	29	44
Depression			
Not depressed	84	71	62
Borderline	12	12	17
Case	4	10	21

Co-morbidities impact multiple aspects of patients' self-reported health status



Role of depression for QOL



- 87 patients with TLE
- Variables examined:
 - Seizure-related
 - Demographic
 - Psychological
- QOLIE-89 scores predicted by:
 - Depression
 - Anxiety
 - ↓ seizure control
 - ↑ seizure severity
 - ↑ epilepsy duration
- Most variance explained by psychiatric morbidity


Role of non-clinical variables in QOL

- Anxiety and Depression
- ‘Burden of normality’
- Stigma, discrimination
- Resilience
 - ‘Cerebral reserve’
 - Outlook
 - Social capital
- Social support
- Perrine et al, 1995; Baker et al 1998, Lerhner et al, 1999; Loring et al, 2004; Johnson et al, 2004; Attarian et al, 2003.
- Bladin, 1992; Wilson et al, 1998.
- Schneider & Conrad, 1981; Scambler, 1989; Jacoby, 1994; Suurmeijer et al, 2001, Baker et al 2001
- Oyegbile et al, 2004
- Jacoby et al, 2001
- Hermann et al, 1990
- Michell et al, 1991; Suurmeijer et al, 2001; Fastenau et al, 2004



IBE Epilepsy and Cognitive Function Survey Results

Ireland

 **Epilepsy and Cognitive Function Questionnaire**

The International League Against Epilepsy (ILAE) in association with IBE, is conducting a survey to gain information on the impact that epilepsy has on cognitive function, memory, attention, thought processes etc. We hope that insights gained from this survey will help to improve understanding of the effects that epilepsy and treatments have on functions such as your ability to think, learn new things, pay attention and remember information.

This short questionnaire will take 2-3 minutes to complete. We would be grateful if you could return your completed form to: ibe@epilepsyireland.ie. Thank you for your assistance.

1) What is your age?				
	<input type="checkbox"/> 18-30	<input type="checkbox"/> 31-40	<input type="checkbox"/> 41-50	<input type="checkbox"/> 51-70
	<input type="checkbox"/> 71+			
2) What is your gender?	Male <input type="checkbox"/>	Female <input type="checkbox"/>		
3) Are you currently taking medication for your epilepsy?	Yes <input type="checkbox"/>	No <input type="checkbox"/>		
If yes, for how long?	<input type="checkbox"/> Months or <input type="checkbox"/> Years			
Are you taking a single medication or Multiple therapies?	Single <input type="checkbox"/> Multiple <input type="checkbox"/>			
4) Since starting treatment, have you experienced any of the following?				
- Forgetting names of familiar people	<input type="checkbox"/> Not at all	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very much
- Retaining a telephone number	<input type="checkbox"/> Not at all	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very much
- Forgetting dates/times, appointments and dates	<input type="checkbox"/> Not at all	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very much
- Forgetting the way around familiar places	<input type="checkbox"/> Not at all	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very much
- Impaired ability to do mental arithmetic	<input type="checkbox"/> Not at all	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very much
- Difficulty paying attention to a speech or news broadcast	<input type="checkbox"/> Not at all	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very much
- Difficulty understanding something you have heard or read	<input type="checkbox"/> Not at all	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very much
- Difficulties learning something new	<input type="checkbox"/> Not at all	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very much
- Slowness of thought	<input type="checkbox"/> Not at all	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very much
- Difficulty following instructions	<input type="checkbox"/> Not at all	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very much
- Impaired eye-hand coordination	<input type="checkbox"/> Not at all	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very much
- Sleepiness/tiredness	<input type="checkbox"/> Not at all	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very much
- Lethargy/happiness	<input type="checkbox"/> Not at all	<input type="checkbox"/> Slightly	<input type="checkbox"/> Moderately	<input type="checkbox"/> Very much

- Nine IBE Chapters selected to participate
 - Austria
 - Denmark
 - Malta
 - Israel
 - Norway
 - Scotland
 - Ireland
 - Belgium
 - France
- 4,500 surveys distributed
- Data of 837 surveys from 9 countries analysed

Experience of cognitive impairment

n = 837

Respondents indicating that they experienced difficulties “very much” or “moderately”

17

Forgetting the way round familiar places

21

Impaired hand-eye coordination

31

Forgetting anniversaries, appointments and dates

32

Forgetting names of familiar people

34

Difficulty paying attention to a speech or news broadcast

35

Difficulty following instructions

35

Difficulty understanding something you have heard or read

35

Impaired ability to do mental arithmetic

37

Retaining a telephone number`

39

Lethargy, sluggishness

41

Difficulties learning something new

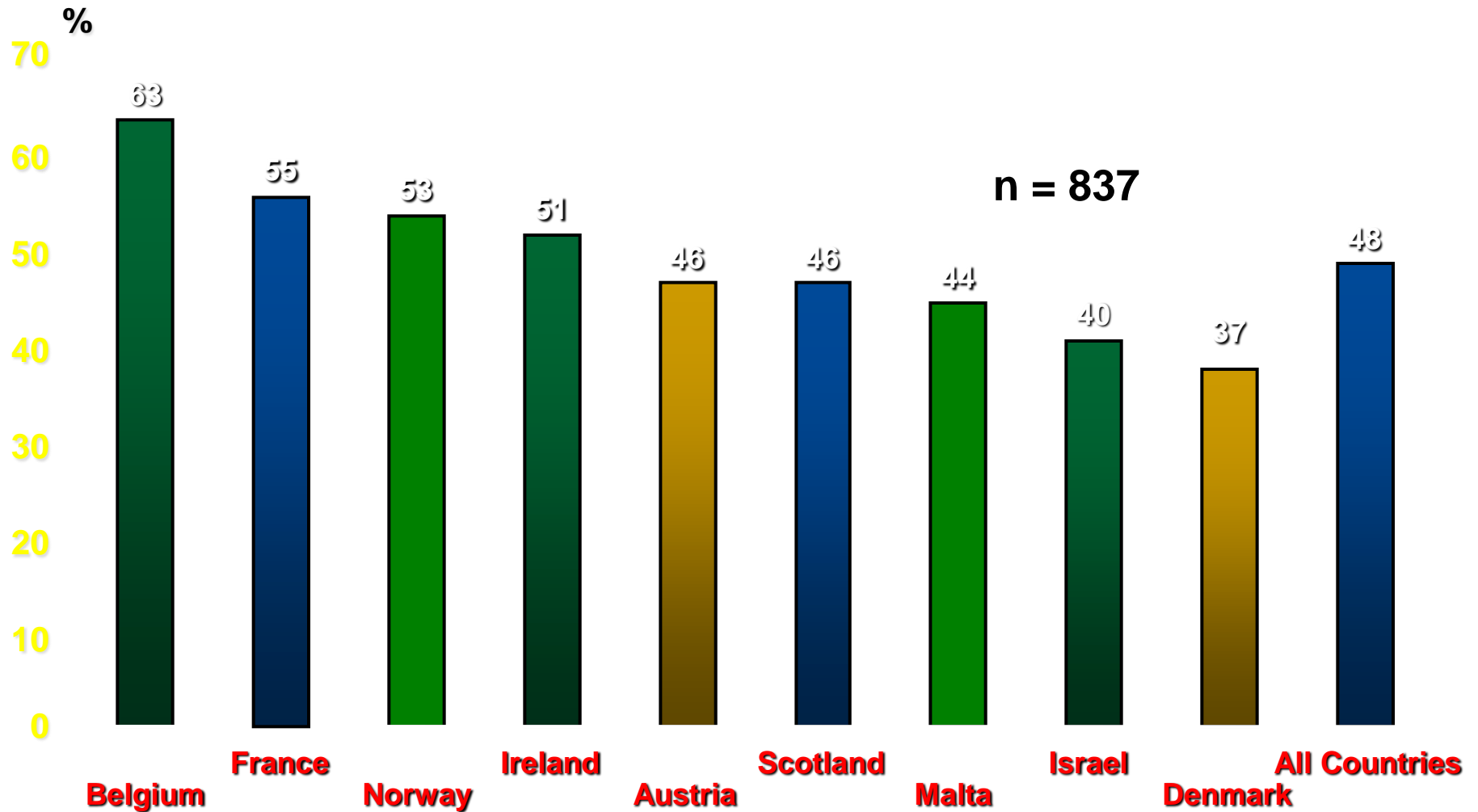
42

Slowness of thought

57

Sleepiness, tiredness

Impact of cognitive impairment on work



**What do we understand about the
long-term impacts of epilepsy on
QOL and
co-morbidities?**

Impact of childhood-onset epilepsy on QOL

- Population-based cohort of 245 children <16yrs, with active epilepsy.
- Followed from 1964 to 1997
- 91 survivors, 91 controls completed QOL questionnaires
- Mean age of epilepsy onset = 4.4yrs
- Mean age at FU = 41.5yrs
- 74 (81%) in remission at FU
- 61 off AEDs; 13 in remission on AEDs

Long-term QOL Outcomes

- Marital status – rates lower cf. controls
 - Offspring – rates lower cf. controls
 - Employment – rates lower if on AEDs
 - Driving – rates lower if on AEDs
 - SES - lower if on AEDs

 - *Conclusions:*
 - *Having Epilepsy has substantial long-term impact, [even if Sz-free and off AEDs]*
-

Questions generated

- How do we support people with epilepsy to minimise the impact of epilepsy and its treatment?
 - How do we change societal attitudes towards epilepsy and reduce stigma – what kinds of intervention are effective?
 - How do we identify who is at risk of developing co-morbidities and impaired QOL? [*biomarkers, psychological and psychiatric risk factors. socioeconomic factors*]
 - How can we intervene to alter the risk of comorbidities and impaired QOL? [*CBT, psycho-educational programmes more aggressive AED treatment - and what works?*].
-

Considerations for future research

- What type of interventions? [*CBT, psycho-educational, AED's, antidepressant medication, surgery*]
 - Where is the evidence of the efficacy of intervention
 - What type of study? [*RCT, observational, Longitudinal e.g. SANAD*]
 - Which groups? [*children, elderly, LD*]
 - Multicentre or single centre?
-



**Thank you for your
attention**
