# patientslikeme ®

Case Study:

Are you sleeping? Real-world insights from patients with chronic conditions

Institute of Medicine

Roundtable on Value and Science-Driven Healthcare

March 12, 2014

"Real-time" knowledge: issues & opportunities

Novel data source with multiple known and unknown biases, requiring new methods, inferences and modeling with limited real world validation

More knowledge begets more questions

Generate

Validate

Verify
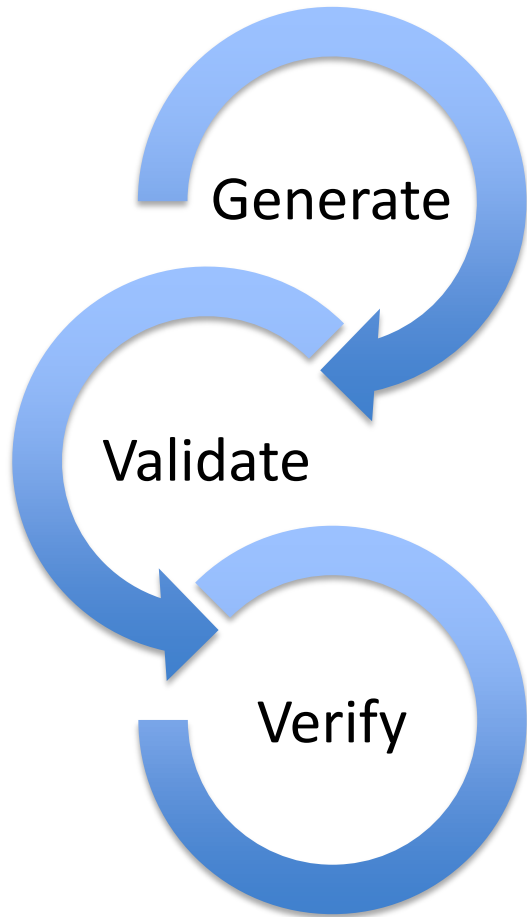
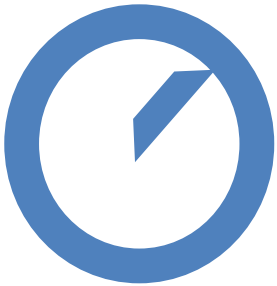*"As our circle of knowledge expands, so does the circumference of darkness surrounding it."*

Albert Einstein

Novel source: patient-generated data

Stratification :

Conditions & Subtypes. Meaningful, computable, measurable, range and variance, of symptomology, biology, pathology, environment, and functional impact of disease

Signal:

Methods, models, & tools that shorten the time to have meaningful confidence about the effectiveness of an intervention in a single patient or model

patients**like**me®

PatientsLikeMe Case Study: Insomnia

- Most people with health conditions have a hard time sleeping well

- Causes are complex and varied including factors such as anxiety, pain, depression, stress

- While common, sleep problems are not generally well assessed clinically

- Sleep deprivation can be hard to spot and quantify

Core data:

225,000+ total members

16MM+ data points

63,000+ reported on insomnia as a symptom **184K+** reports
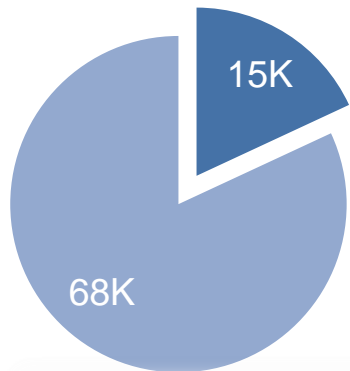
70%+ with moderate/severe insomnia

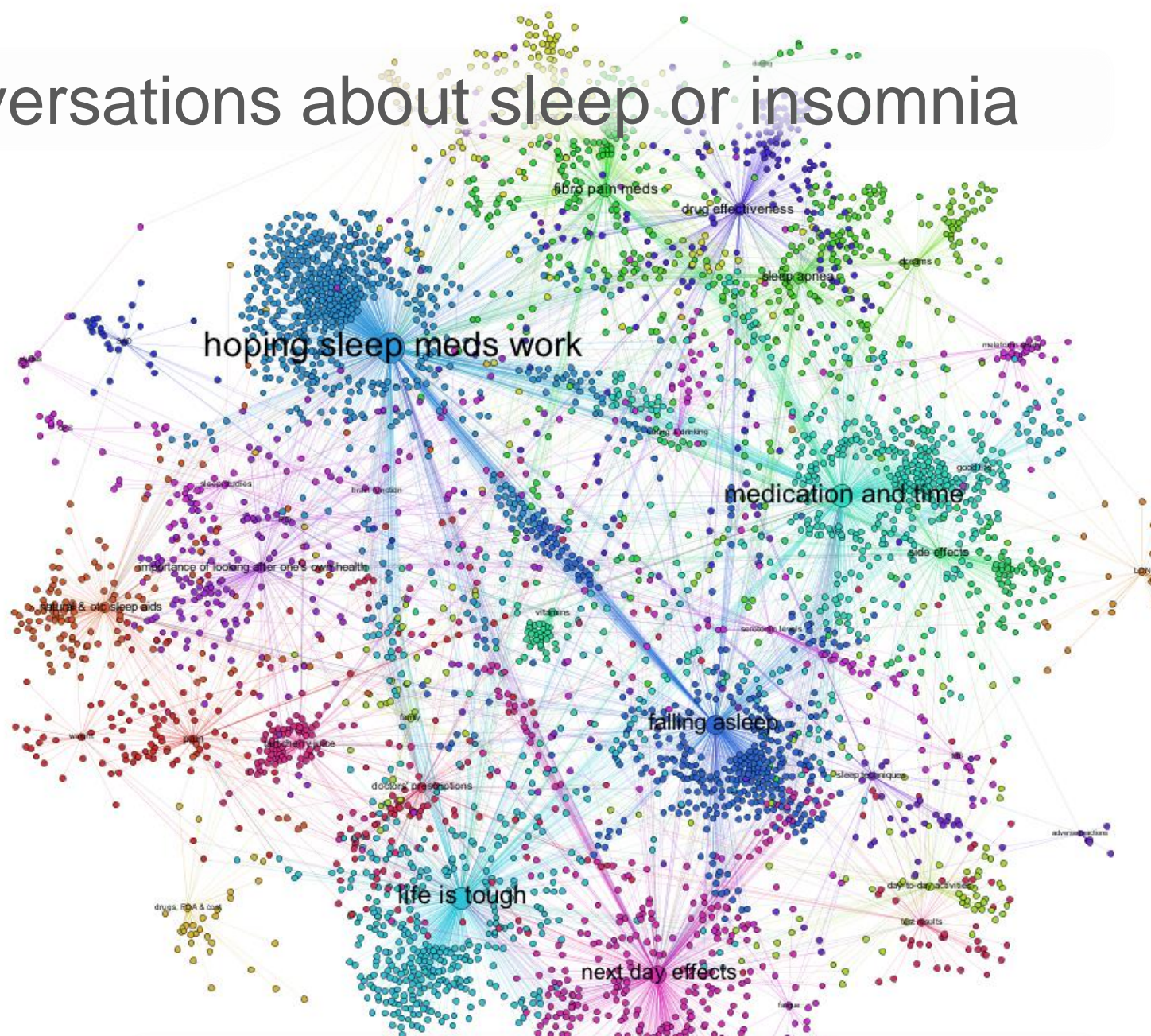**83K+** forum posts mentioning sleep/insomnia

Rapid Research in 2013

90 question sleep survey by **5K+** members in 2 weeks

patientslikeme®

# ~83K conversations about sleep or insomnia

Main topic:

Hoping sleep meds work

15K

68K

Meds as a proportion of conversations about sleep or insomnia

hoping sleep meds work

fibro pain meds

drug effectiveness

sleep apnea

dreams

melatonin

medication and time

side effects

importance of looking after one's own health

natural & otc sleep aids

vitamins

serotonin levels

falling asleep

sleep techniques

doctors prescriptions

life is tough

next day effects

adverse reactions

day to day activities

drugs, FDA & cost

Source: PLM free-text forums N=4,405. Text is sized according to the relative popularity of this topic as indicated by the number of posts about it.

7

patientslikeme

Patient voice describes "my insomnia"

- Awakening due to numbness
- Complete inability to sleep (not merely insomnia)
- Difficulty sleeping
- Difficulty sleeping occasionally
- Difficulty sleeping on left side
- Difficulty sleeping through night
- Difficulty sleeping on full dose
- Difficulty staying asleep
- Frequent waking
- Inability to sleep

- Insomnia if dose taken late or missed
- Lack of sleep
- Less than 2 hours sleep
- Loss of sleep
- Rebound insomnia
- Segmented sleep
- Sleep anxiety
- Sleep disturbances
- Sleeplessness
- Sleeplessness for first month
- Sleep problems
- Unable to sleep for > 4 hours
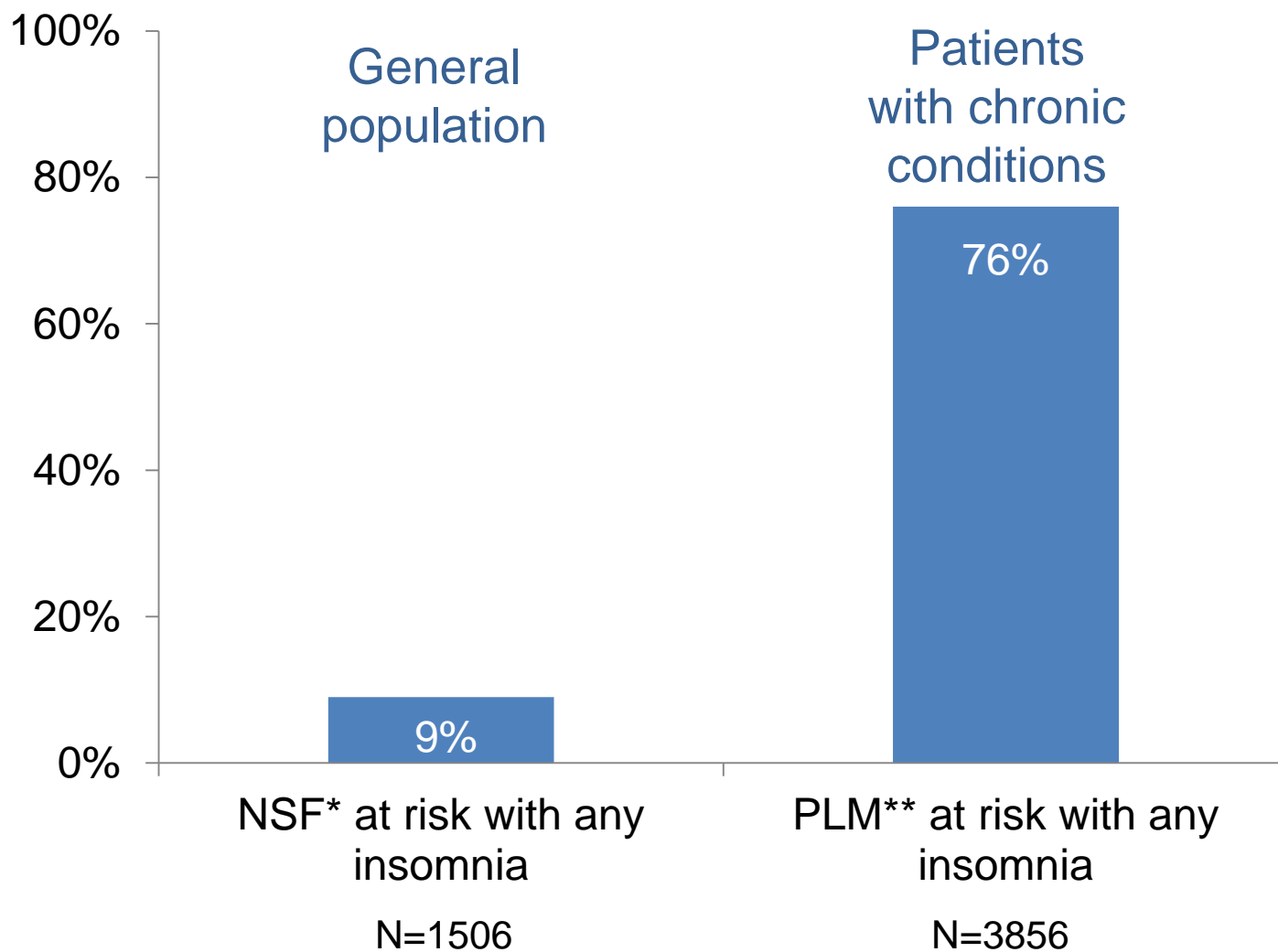
Logins by time of day (users local time)
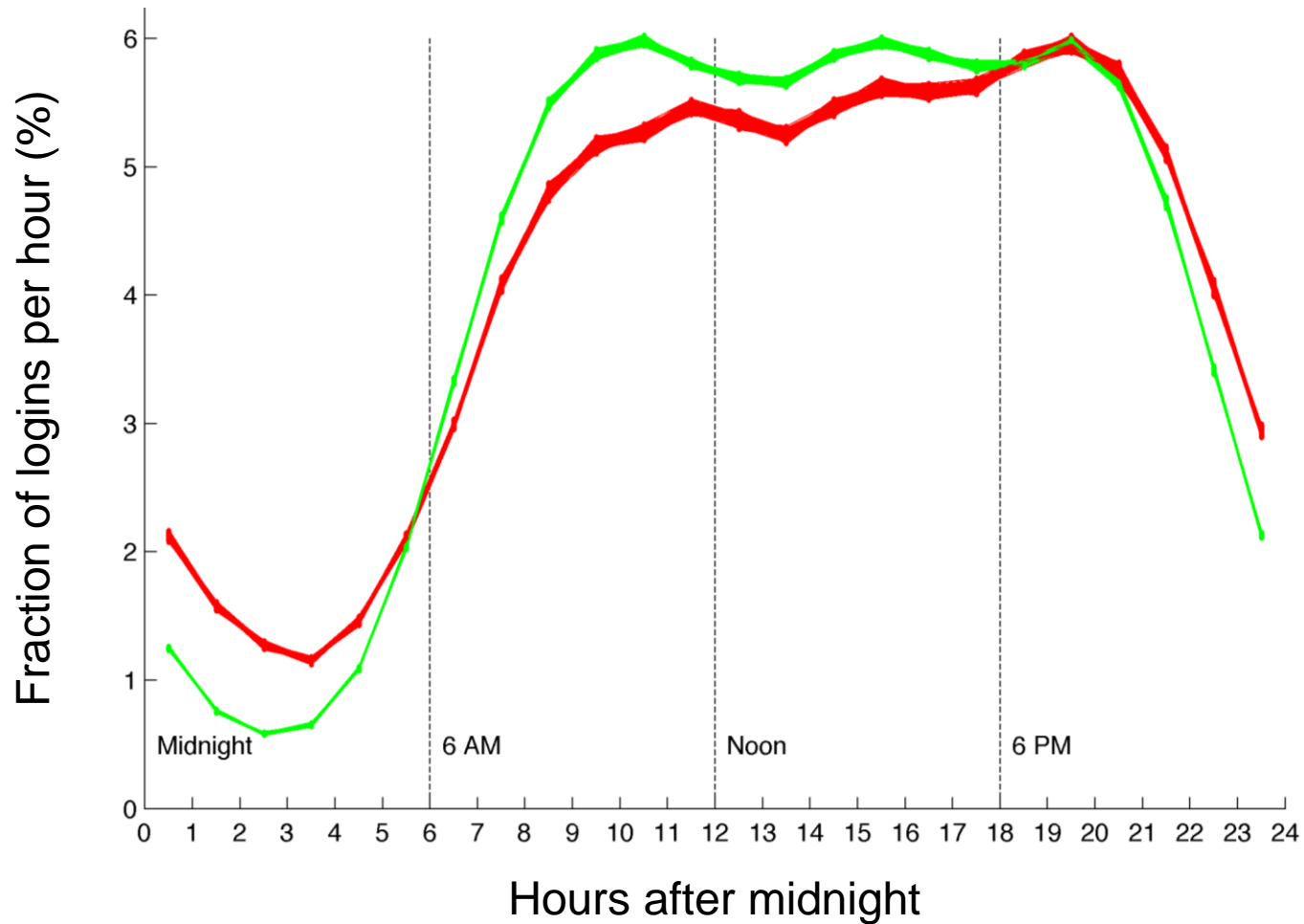
General sleep issues

patientslikeme®

Risk of insomnia

PLM vs 2005 National Sleep Foundation
4 subtypes of sleep problems in past year
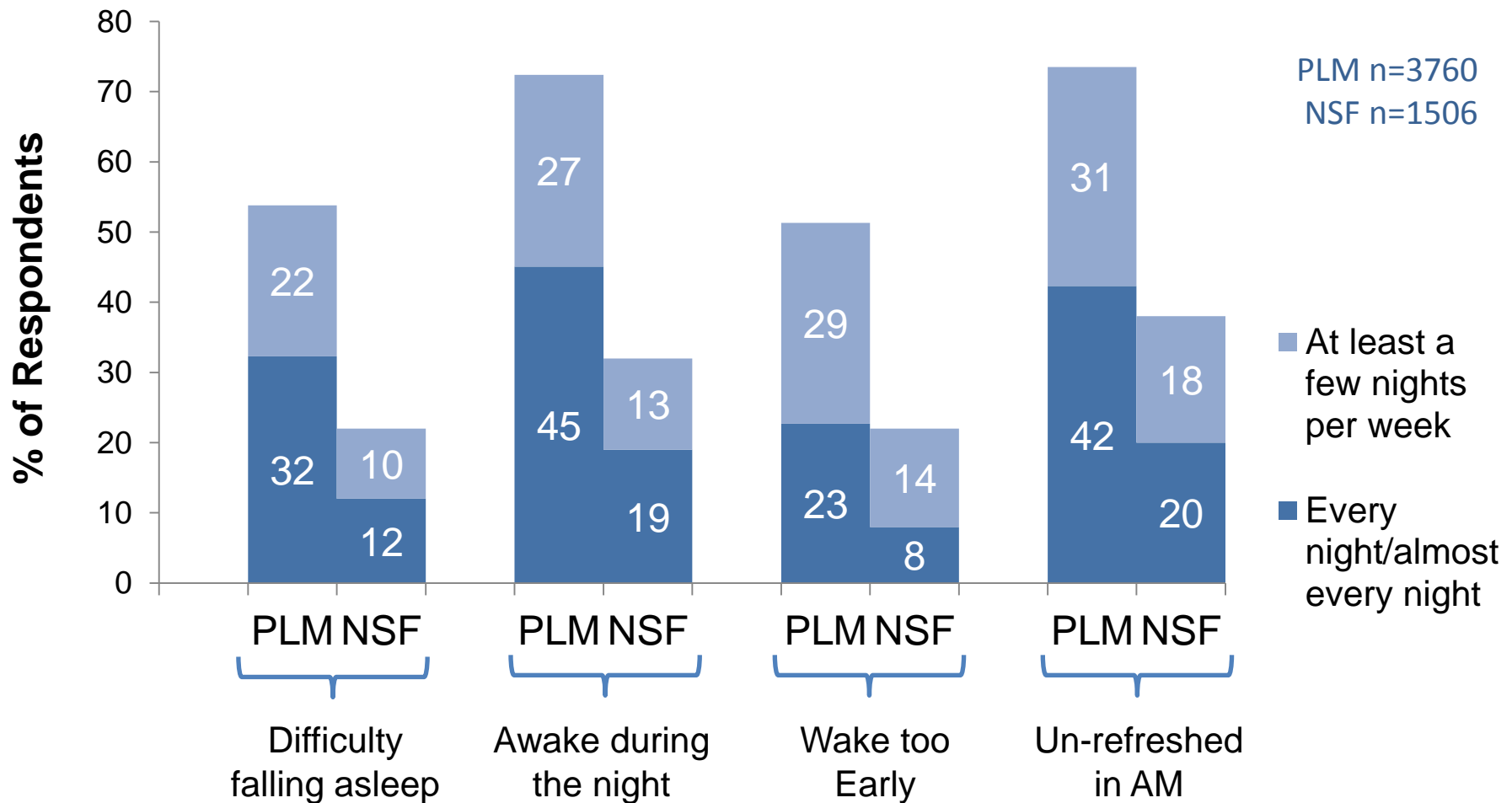
PLM n=3760
NSF n=1506

% of Respondents

Legend:
- At least a few nights per week
- Every night/almost every night

Data (PLM / NSF):
- Difficulty falling asleep: PLM 22 (few nights) / 32 (every night); NSF 10 (few nights) / 12 (every night)
- Awake during the night: PLM 27 / 45; NSF 13 / 19
- Wake too Early: PLM 29 / 23; NSF 14 / 8
- Un-refreshed in AM: PLM 31 / 42; NSF 18 / 20

patientslikeme®

12
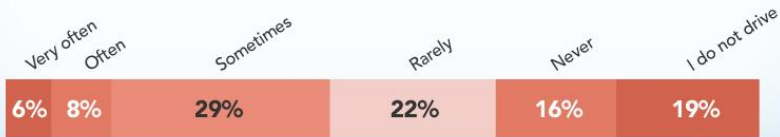
Impact of insomnia on people's daily life & relationships
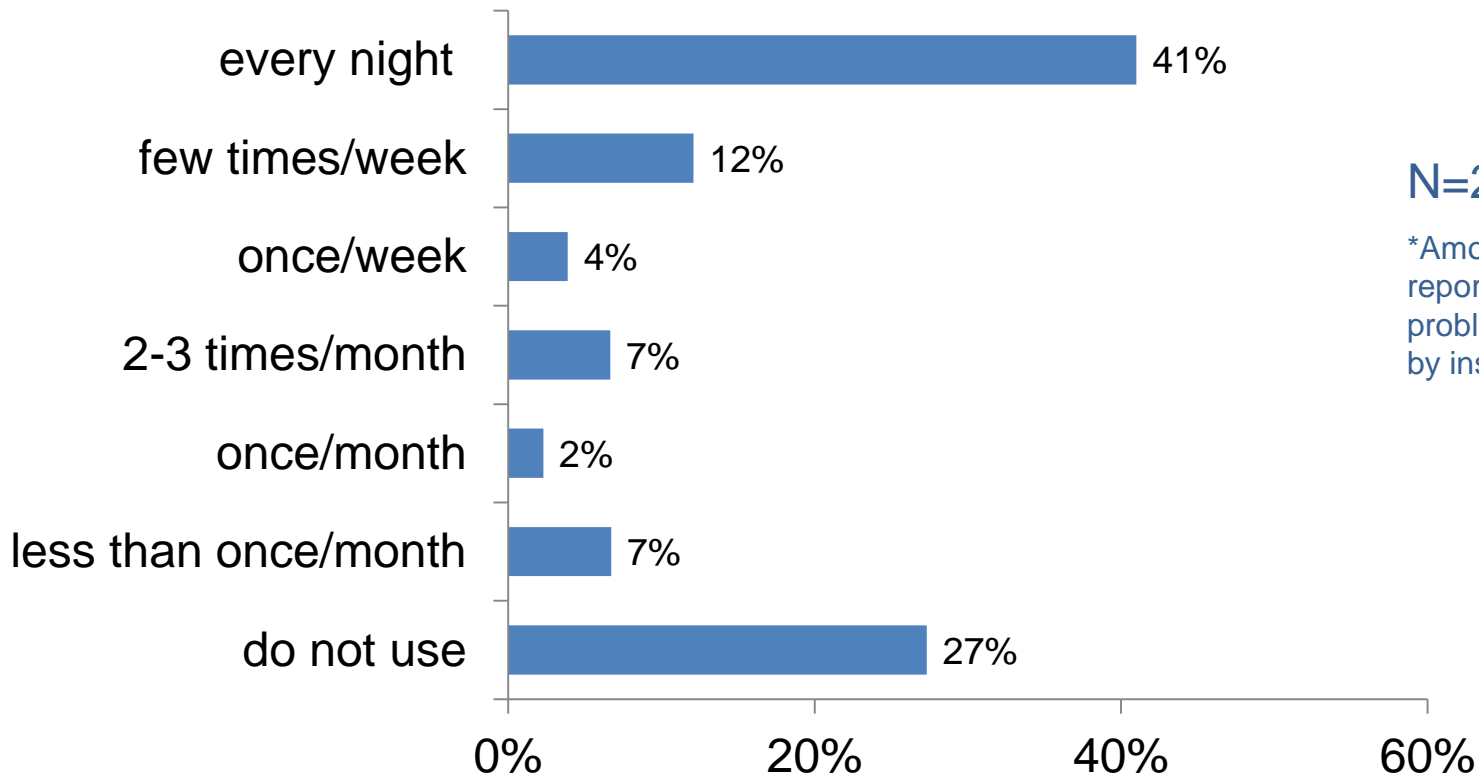
Sleep Medication Experience

PLM survey respondents reporting current or past use
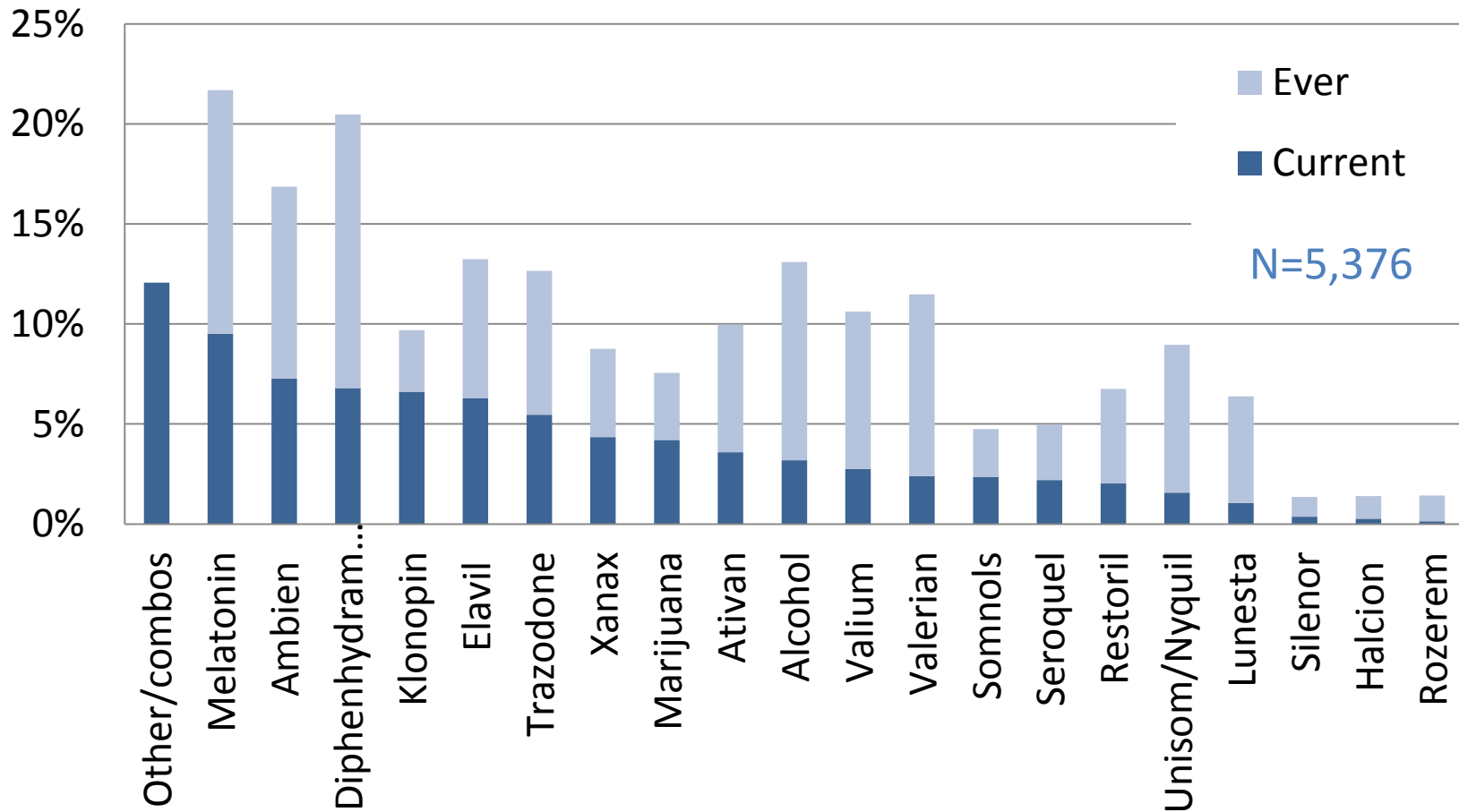
Among those who report taking medications currently to help them sleep, the most widely taken are melatonin (n=512), Ambien (n=391), diphenhydramines (Tylenol PM/Benadryl) (n=365), Klonopin (n=355) & Elavil (n=338).

patientslikeme®

14

Complex tuning by patients

"I take my LDN as my head hits the pillow, and fall asleep easily. I take a benadryl and cherry juice about an hour before my bedtime. I sleep sound and wake at 7am well rested. For 10+ years sleep was a big problem and I took Ambien for abut 8 years, until it stopped working."

"…And a cocktail I'm embarrassed to talk about but wouldn't give up for anything right now - - 3mg Requip , 600mg Neurontin (takes care of pain and sedates), 100mg trazodone , 1mg Xanax. I don't wake up feeling hung over. But, I built up to this under drs supervision. I don't like taking all that, but I've tried without and don't get sleep then am useless at work the next day 'cause I can't move and hurt all over and am GRUMPY!"

"I take 150 mg of Effexor XR and have been taking it for about five months. I do have a problem with insomnia so I take 50 mg of Benadryl at night. I also take 50 mg of Seroquel at night to help with sleep. I recently added Lithium to my cocktail."

Distribution of insomnia severity by condition
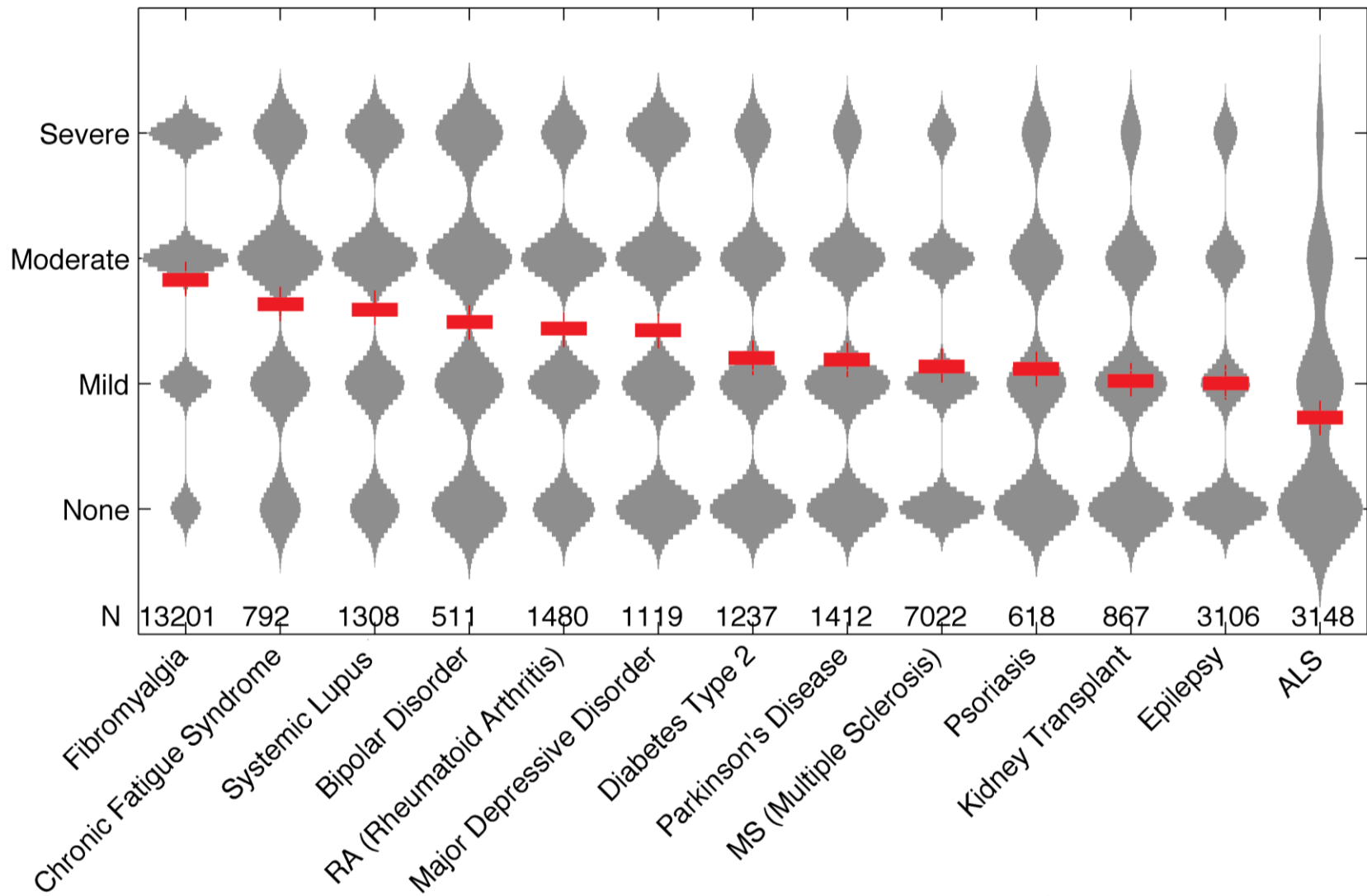
Unexpected Finding

Fibromyalgia data caused us to evaluate insomnia correlations

Spearman's rho` Spearman/Kendall correlations Insomnia (none, mild, moderate, severe) vs. PFRS component: (none, a bit, some, most, and all) of the time	can't fall asleep	Not enough sleep	wake not rested	wake achy	wake stiff
Insomnia	0.69	0.51	0.37	0.26	0.24
Depressed mood	0.28	0.25	0.25	0.24	0.23
Pain	0.29	0.31	0.30	0.42	0.39
Fatigue	0.30	0.42	0.45	0.33	0.30
Anxious mood	0.25	0.26	0.25	0.24	0.24
Balance problems	0.23	0.27	0.25	0.27	0.29
Brain fog	0.24	0.31	0.33	0.31	0.30
Headaches	0.23	0.24	0.24	0.22	0.20
Pain in lower back	0.26	0.26	0.24	0.33	0.32
Muscle spasms	0.27	0.28	0.25	0.31	0.32
Muscle and joint pain	0.28	0.30	0.31	0.45	0.44

N: 14,728 patients,   22,566 reports

Can we predict insomnia?

Regression model of insomnia vs other symptoms

Insomnia = α + β^ddepression + β^ppain + β^ffatigue + β^aanxiety

= 0.17 + 0.12*depression + 0.24*pain + 0.24*fatigue+ 0.16*anxiety

Symptoms on a scale [None,Mild,Mod,Severe] = [0,1,2,3]

Prospecting for "real-time" knowledge

"All models are wrong, but some are useful"   George Edward Pelham Box

- Learn about the *lives of patients* not just their care

- Work across diseases to *highlight differences and leverage scale*

- Make patients partners in the process – they *light the path to knowledge* with their experiences and insights

patients**like**me®