



Outcomes Measurement in Palliative Care

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**The ultimate measure of
the quality of health
care is the outcomes
that patients and carers
achieve**



The Palliative Care Outcomes Collaboration (PCOC)

A national initiative funded by the Department of Health & Ageing to introduce routine assessment of palliative care quality and outcomes across Australia

PCOC:

- Supports continuous quality improvement of palliative care
- Benchmarks service to improve practice
- Measures outcomes (service and patient/carer)
- Standardises palliative care assessment
- Develops a “common language” for clinicians including primary care



How PCOC works

- Work with services to incorporate the PCOC patient outcome measures into routine practice
- Provide ongoing support through training and assistance with IT
- Analyse the data and provide feedback on the results to individual services - reports every 6 months
- Facilitate benchmarking with other services
- Assist services with practice quality changes



Overview of Progress (1)

- 111 palliative care services (of about 160 in Australia) have agreed to join PCOC so far, with 85 submitting data for last PCOC Report
- Majority are large metropolitan services
- Estimate is that these services represent more than **80%** of specialist palliative care episodes
- All other specialist PC services across Australia are at various stages of follow up, with most expected to join



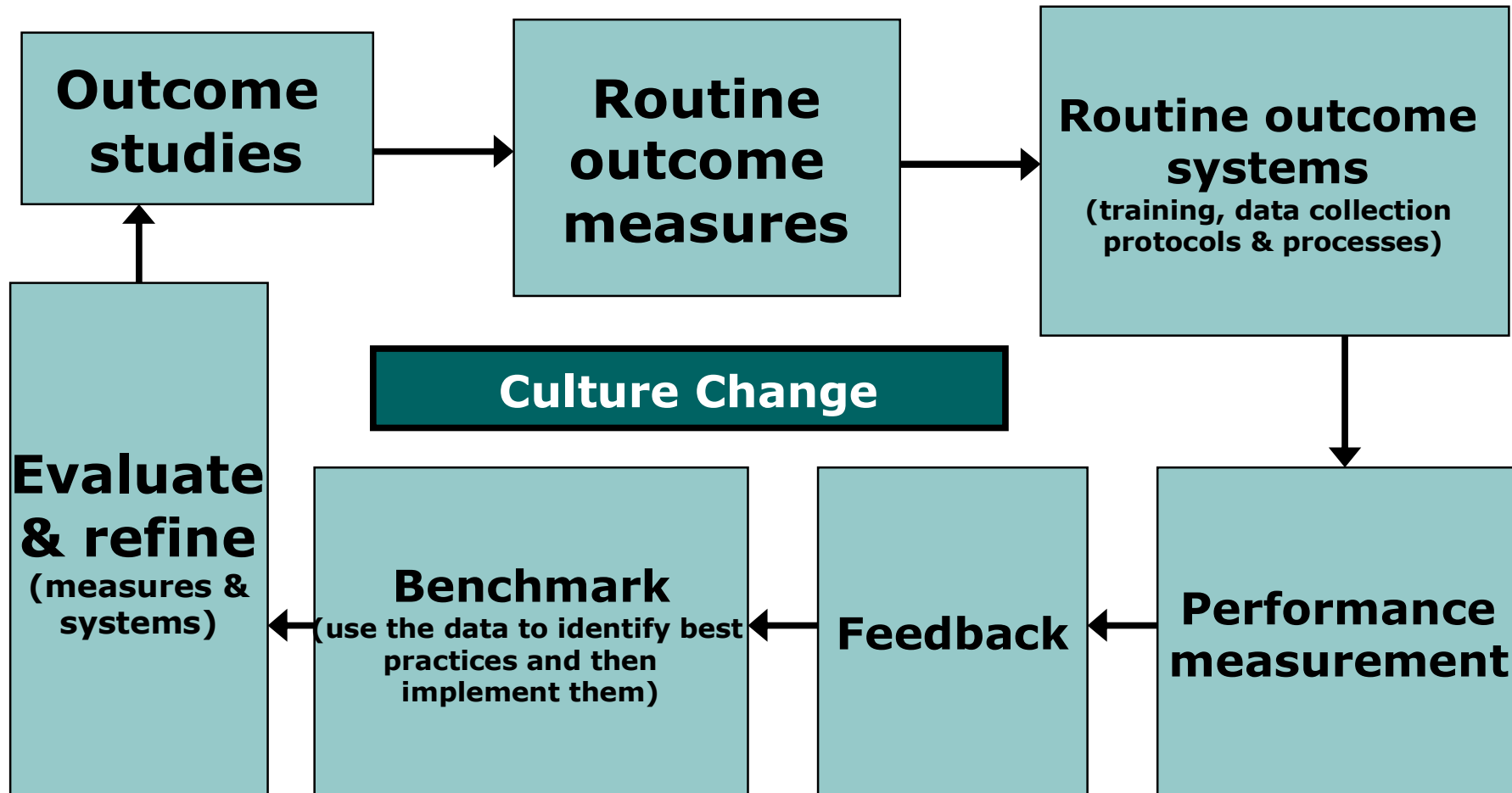
Overview of Progress (2)

- Seven national reports
 - Report #7 covers 1 Jan to 31 Jul 2009
- Annual national patient and carer surveys
- Over 2,500 clinicians trained
- Three national benchmarking workshops in 2009
- Early stage planning for V3 dataset of the patient outcomes data set has started



PCOC benchmarking

The PCOC benchmarking cycle





PCOC information architecture

- **Level 1 Patient**
 - eg, age, sex, diagnosis, postcode
- **Level 2 Episode of palliative care**
 - eg, referral source, time between referral & 1st assessment, episode type, accommodation at start & end, level of support at start & end, place of death
- **Level 3 Phase**
 - eg, Phase (stable, unstable, deteriorating, terminal, bereaved), function at start & end, symptoms at start & end, reason for phase end

3 initial benchmark measures

- Time between referral and 1st contact
- Change in pain from beginning to end of phase
- Time in unstable phase
- Next step is to introduce 3-4 additional measures. Under consideration are:
 - psychological/spiritual problems- PCPSS (Palliative Care Problem Severity Score)
 - carer problems- PCPSS
 - nausea – SAS (symptom assessment score)
 - fatigue - SAS
 - dyspnoea - SAS



A constant theme - unexplained variation

No matter what the measure, we find significant variations between services that we are working to understand and reduce

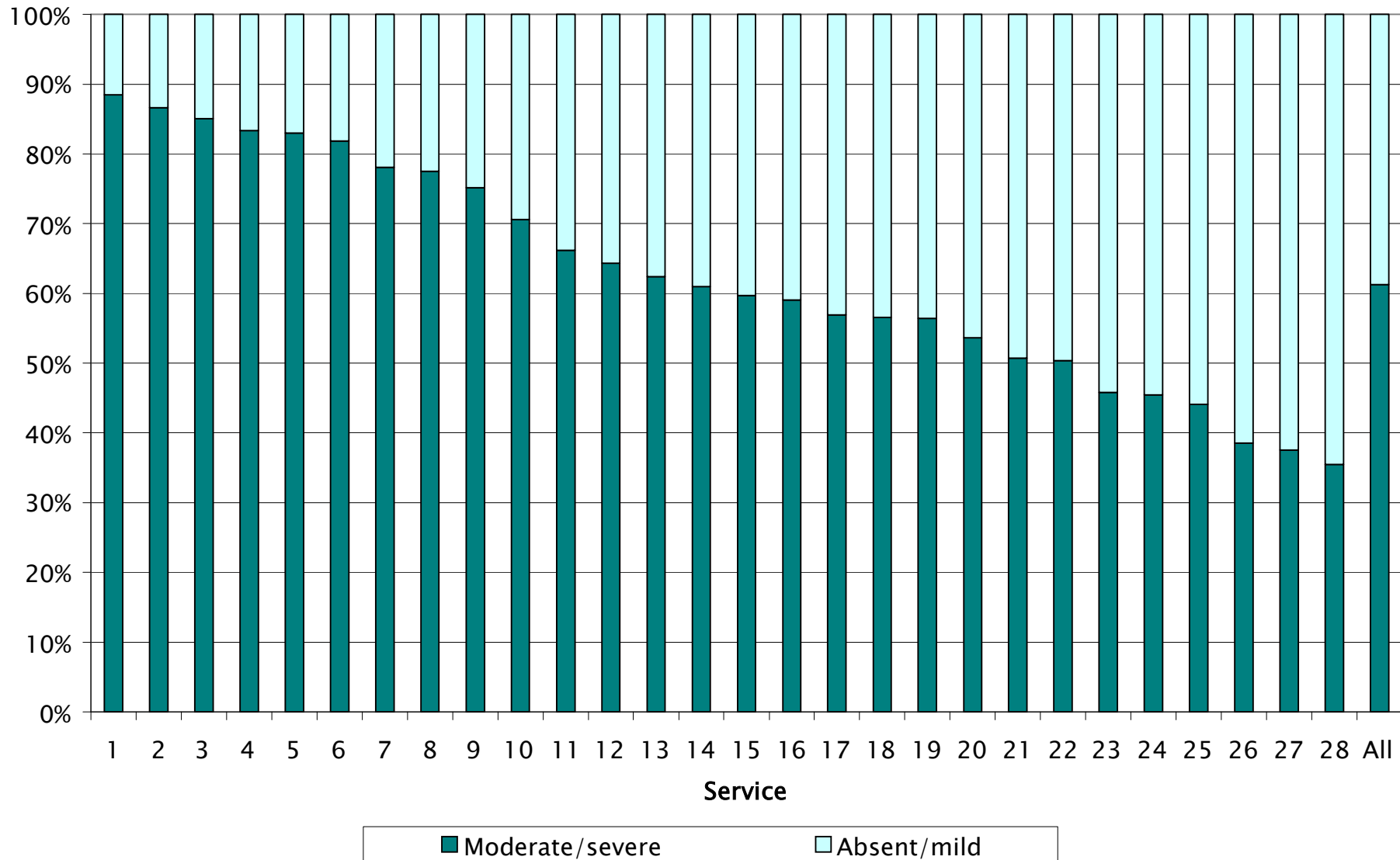
Some examples...

Variability among inpatient units

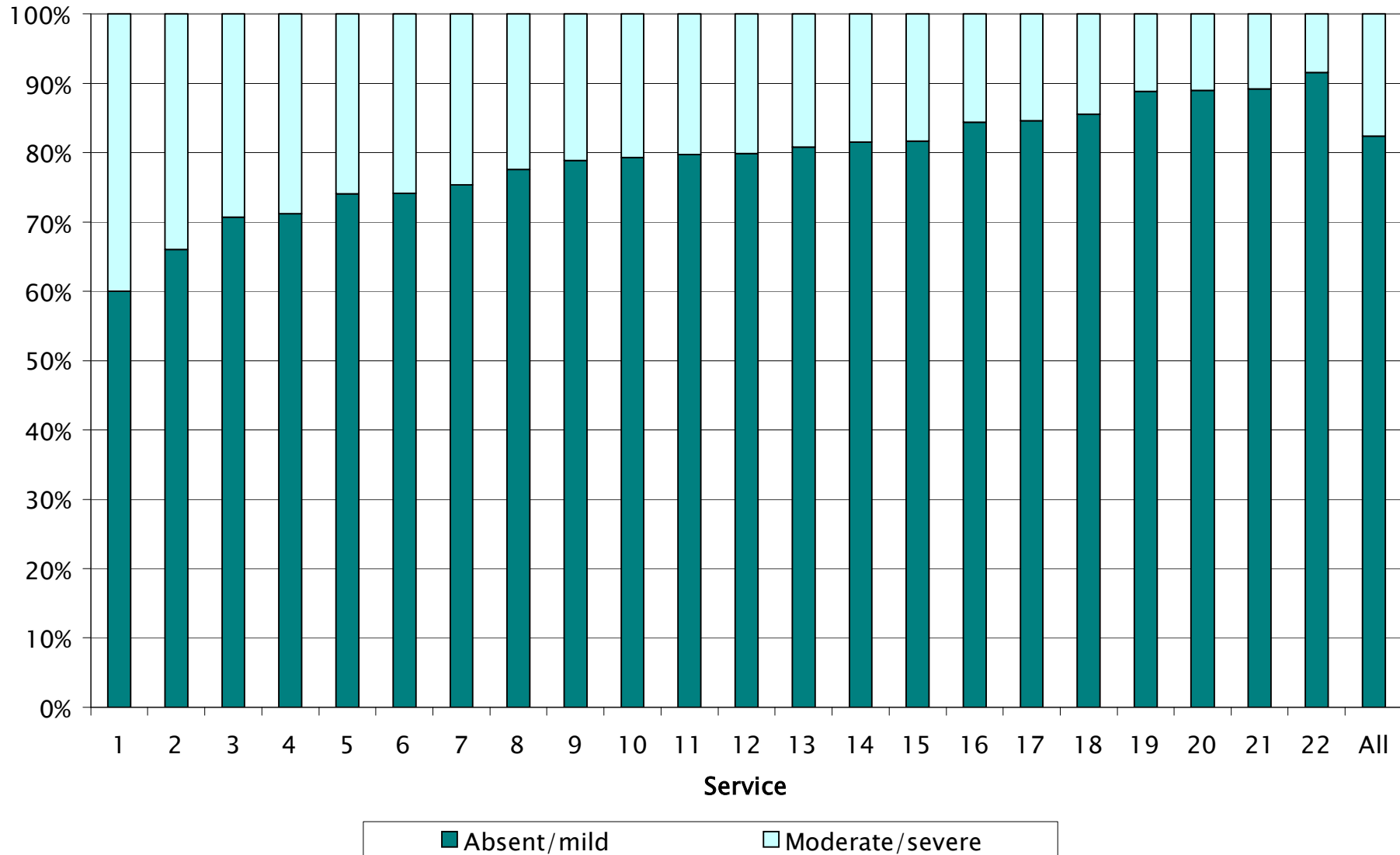
Measure	Mean	Min	Max	SD	Difference (Xfold)
Average length of stay	14.0	6.2	18.6	3.3	3
Discharge to community	25.1%	12.1%	64.2%	15.4	5
Stable after unstable	25.9%	4.2%	51.5%	16.2	12
Function better	9.8%	3.6%	15.7%	3.6	4
Symptoms improve	22.4%	5.8%	40.6%	11.2	7

The picture is no different for community and consultative services

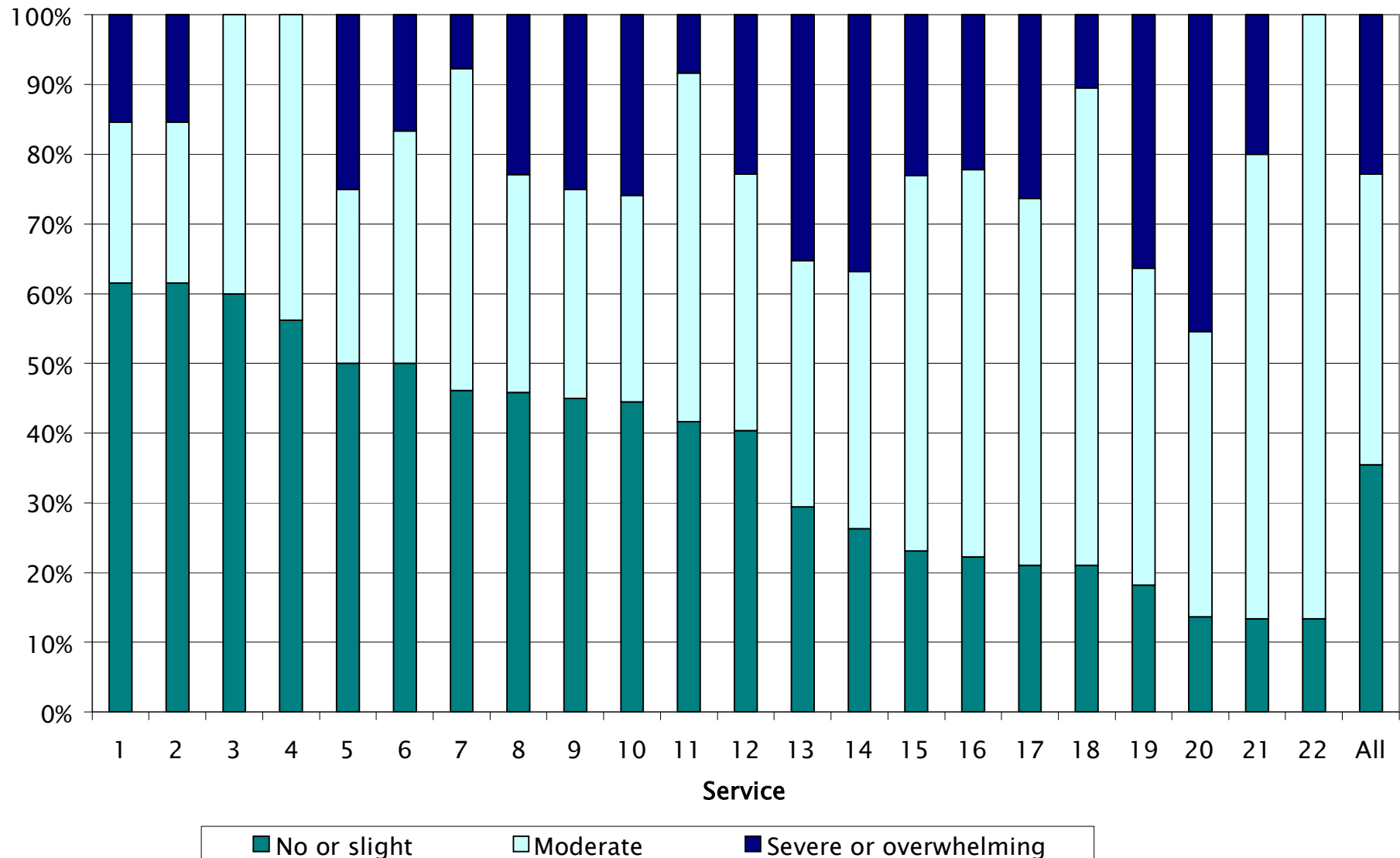
Pain at phase end for patients with moderate or severe pain at start (SAS)



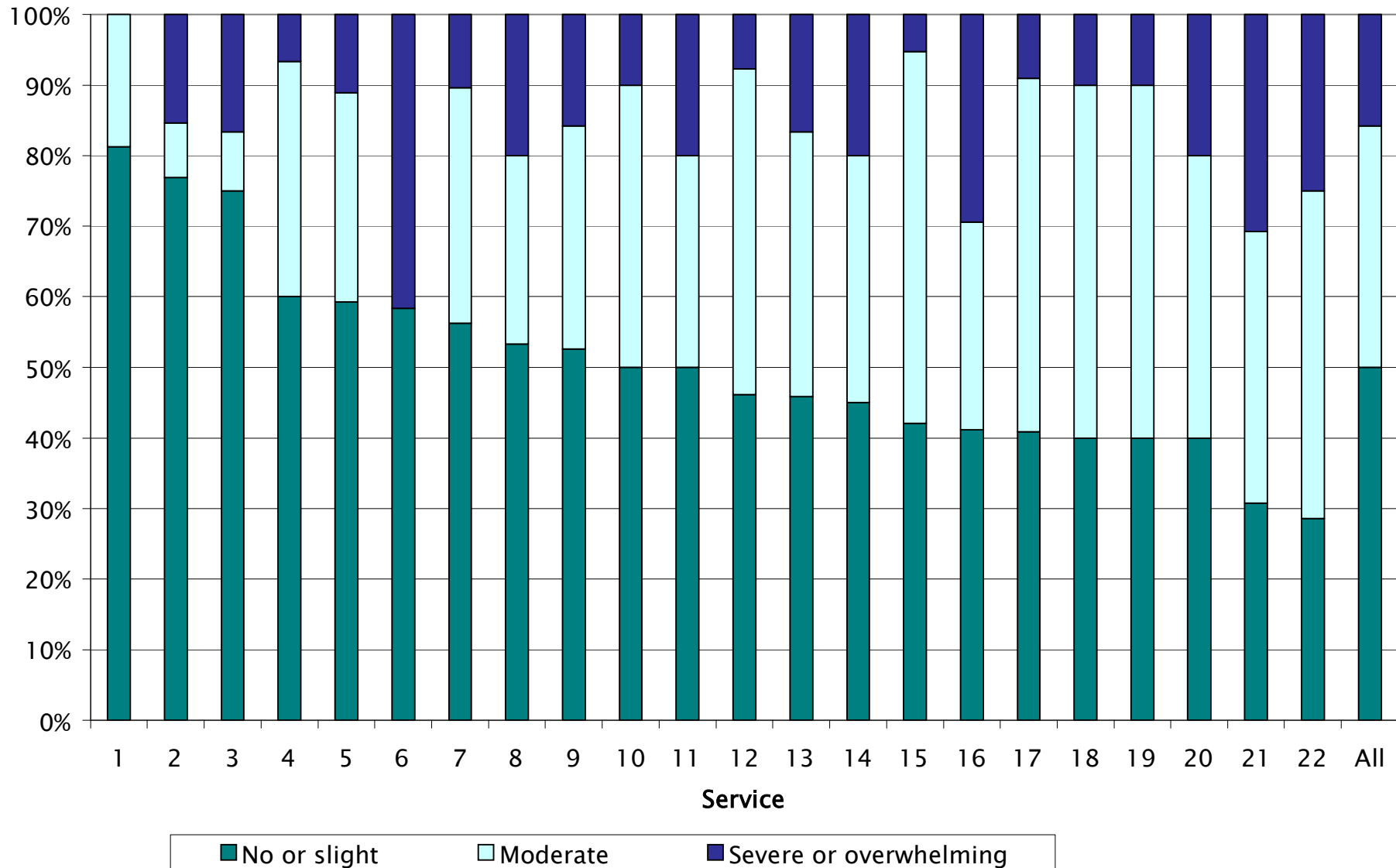
Pain at phase end for patients with no or mild pain at start (SAS)



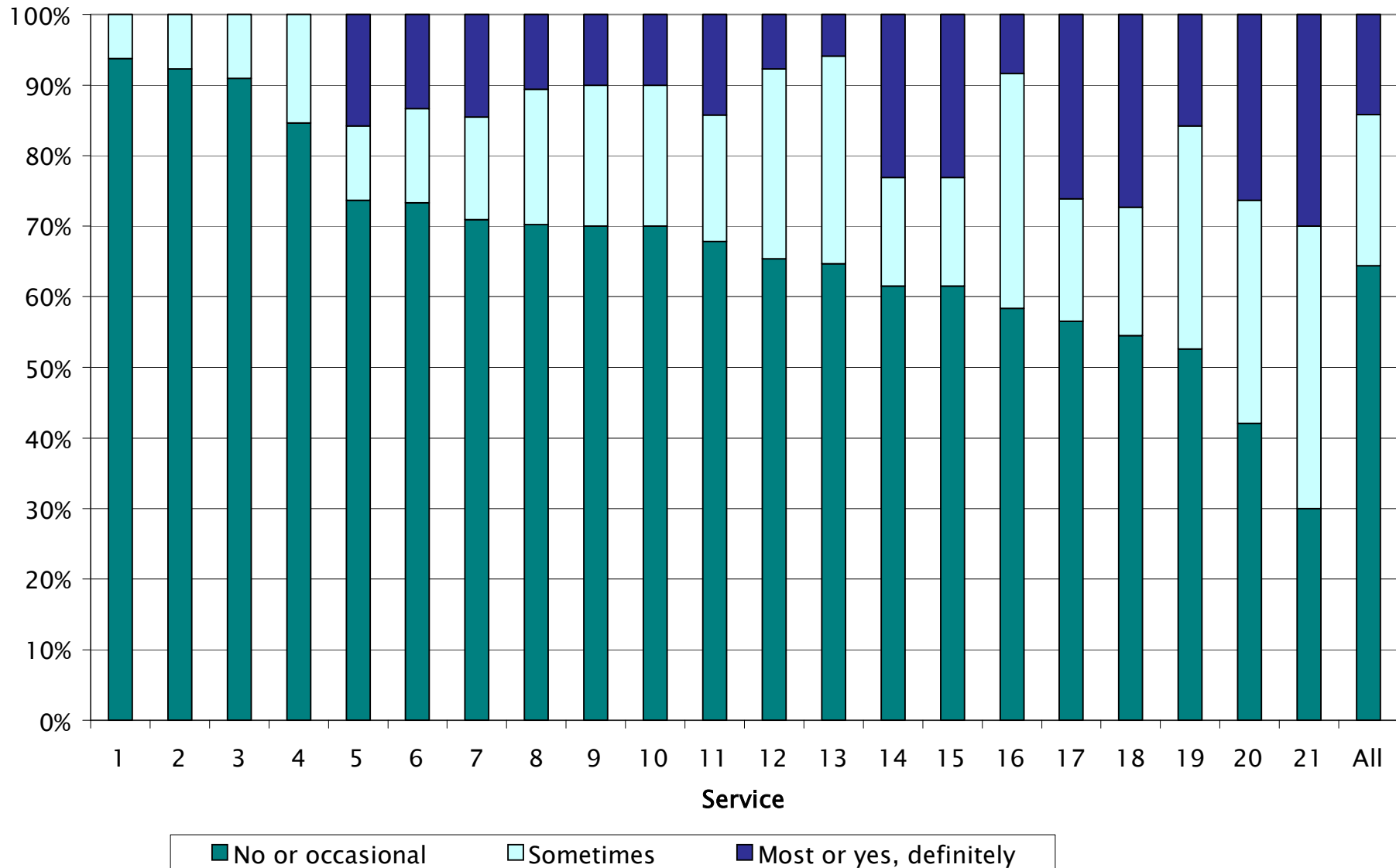
Patients self-reported pain in last 3 days (POS-2)



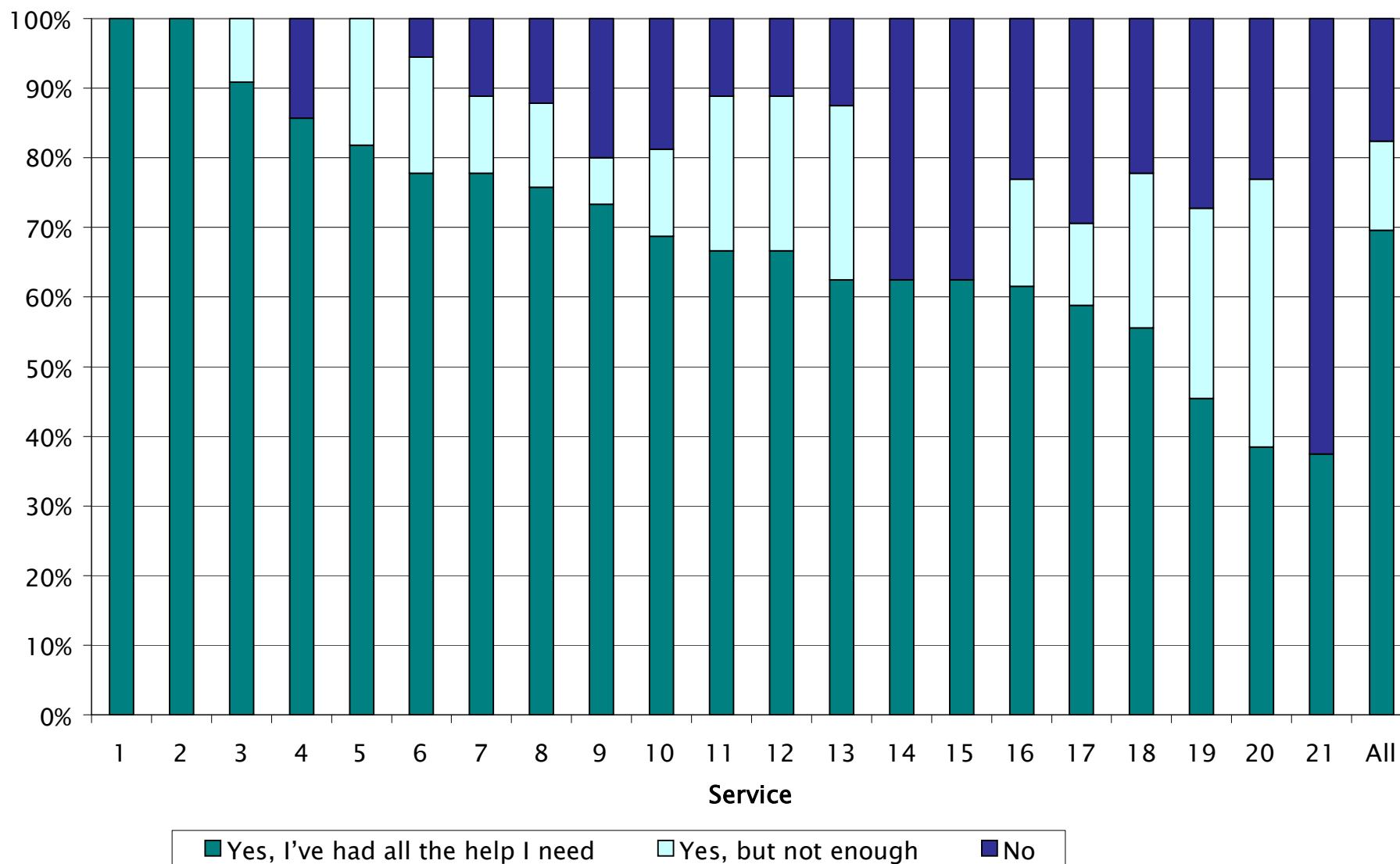
Patients self-reported other symptoms in last 3 days (POS-2)



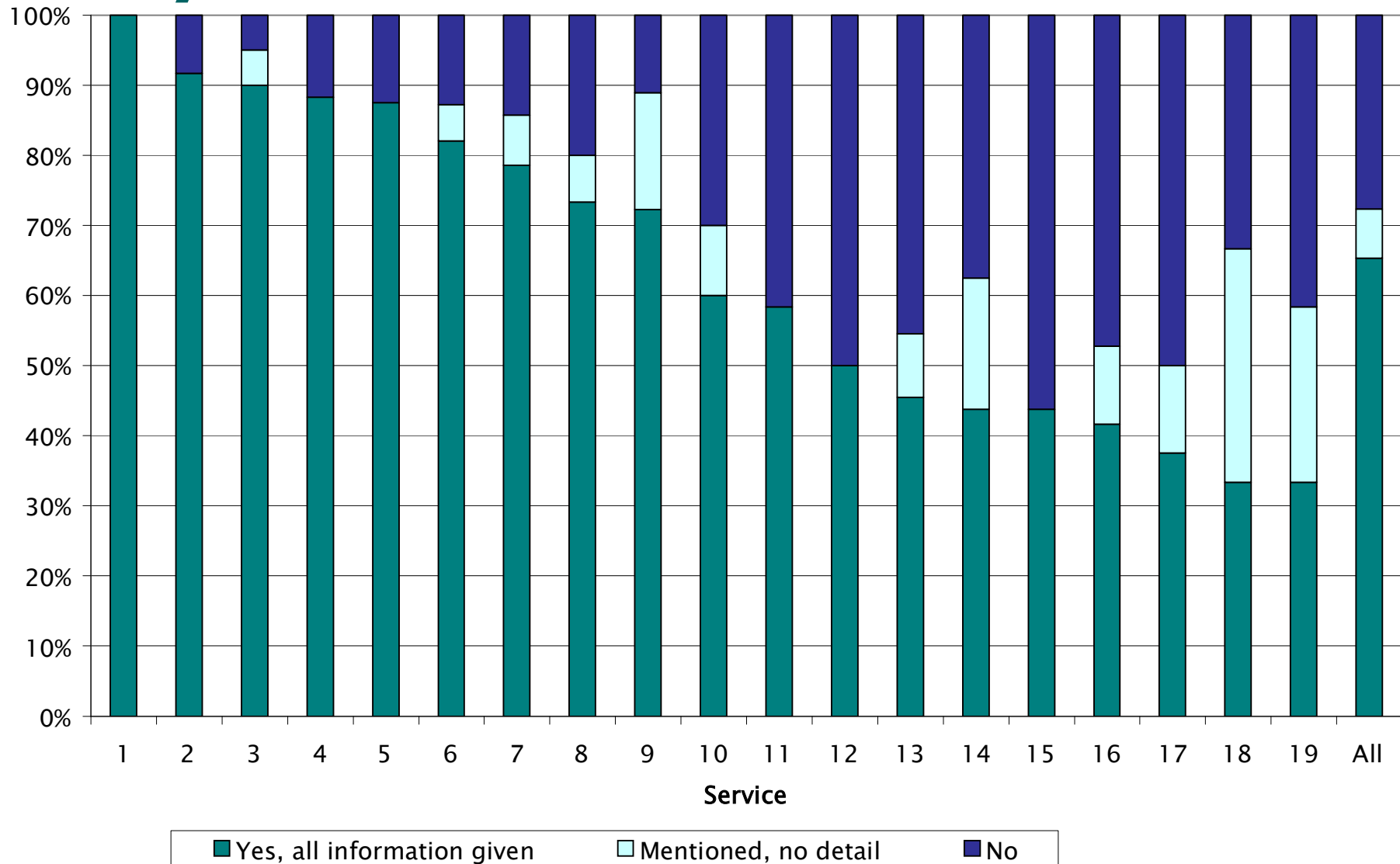
Patients self-reported depression in last 3 days (POS-2)



Carers - Have you had someone to help you with practical tasks?



Carers - Information on Carer Payment or Allowance?





An increasingly sophisticated evidence-based sector

- Early days - 'We don't need to measure outcomes, our patients and carers are really satisfied with the care we provide'
- Then - 'The data must be wrong'
- Now - 'We now have information we've never had before. What does this mean for the way we provide care? How can we improve the way we organise our service?'



Conclusion

PCOC goal is to work with services to optimise the quality of care and to minimise variations in practice that compromise patient and carer outcomes

The demonstrated variability justifies investment in routine data collection and benchmarking between services

Significant progress so far but a long way to go!