



We Care Journey
#thinkSMA~~L~~actBIG

The Right to Health & Life

How Better Cost Control

Can Ensure

Broad & Equitable

Access to Medicines

Presented by Edmund Lim

Where I'm coming from

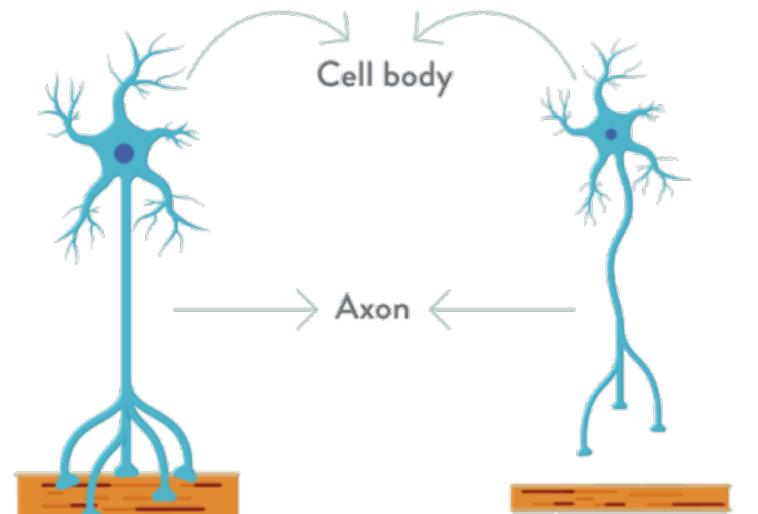
Parent



Financially literate



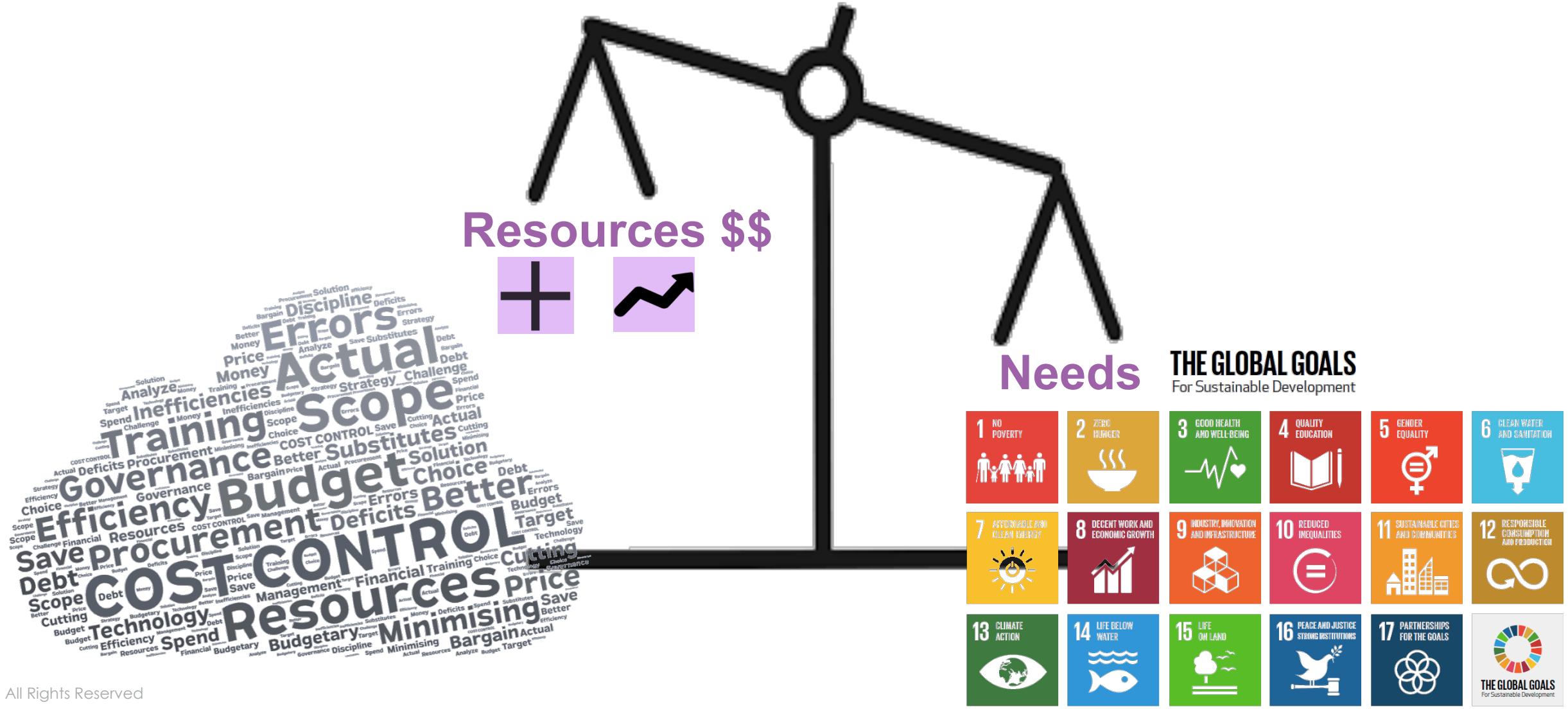
Motivated & Stressed



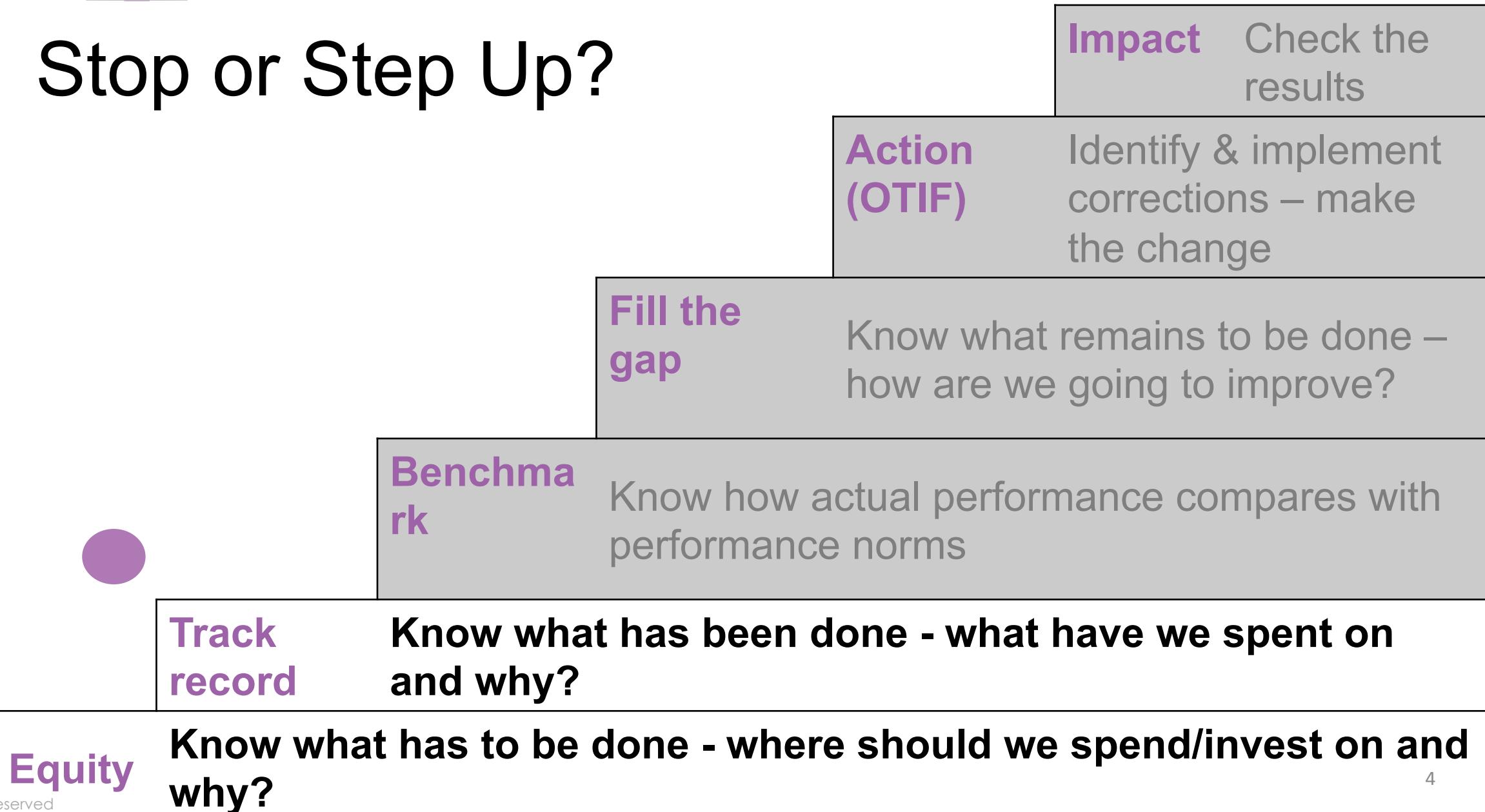
Normal nerve and muscle cell

SMA-affected nerve and muscle cell

Stress = Needs > Resources



Stop or Step Up?



Who are the most vulnerable? - needs Who gets the most help? - spend

Undiagnosed
or wrongly
diagnosed

- No standards of care

Diagnosed

- No disease modifying treatments available

Disease
modifying
treatments

- But no or some access only



Disease
modifying
treatments
available

- But how sustainable?

Stop or Step Up?

Track record

Know what has been done - what have we spent on and why?

Benchmark

Know how actual performance compares with performance?

Fill the gap

Know what remains to be done – how are we going to improve?

Action (OTIF)

Impact Check the results

~ 50 countries access to Spinraza

Countries both richer and poorer than Malaysia

Austria	Reimbursed access – all patients
Belarus	Dossier not yet submitted
Belgium	Reimbursed access – all patients who do not require permanent mechanical ventilation
Bulgaria	Dossier not yet submitted
Croatia	Reimbursed access – patients < 18 years old who are not on mechanical ventilation
Cyprus	Individual reimbursement
Czech Republic	Reimbursed access – patients with SMA type I, II and IIIa (subject to clinical criteria)
Denmark	Reimbursed access – patients with SMA types I and II (subject to clinical criteria) as well as pre-symptomatic patients
England & Wales	Reimbursed access – pre-symptomatic patients and patients with SMA types I, II and III, excluding type IV (adult-onset) patients
Estonia	Pricing negotiations under way
Finland	Reimbursed access – patients with types I and II < 18 years old
France	Reimbursed access – all patients
Germany	Reimbursed access – all patients
Greece	Reimbursed access – patients with SMA types I and II as well as pre-symptomatic infants; negotiations under way
Hungary	Individual reimbursement – patients < 18 years old
Iceland	Reimbursed access – patients < 18 years old
Ireland	Pricing negotiations under way; Biogen's humanitarian programme in place for children with SMA type I
Italy	Reimbursed access – all patients
Latvia	Dossier not yet submitted
Lithuania	Individual reimbursement – patients with SMA types I, II and IIIa
Luxembourg	Reimbursed access – all patients
Malta	Reimbursed access via a named patient programme
Netherlands	Reimbursed access for patients < 9.5 years old (subject to clinical criteria); remaining patients via Biogen's humanitarian programme
Northern Ireland	Pricing negotiations under way; Biogen's humanitarian programme in place for children with SMA type I
North Macedonia	Pricing negotiations under way
Norway	Reimbursed access – patients < 18 years old
Poland	Reimbursed access – all patients (including presymptomatic)
Portugal	Reimbursed access – all patients
Romania	Reimbursed access – all patients
Russia	Dossier submitted; Biogen's humanitarian programme in place for children with SMA type I under clinical criteria

Scotland	Reimbursed access – all patients
Serbia	Access through a named-patient programme depending on funding availability
Slovakia	Reimbursed access – patients with SMA type I, II and IIIa
Slovenia	Reimbursed access – patients with SMA type I, II and IIIa
Spain	Reimbursed access – all patients (subject to clinical criteria)
Sweden	Reimbursed access – patients initiated below 18 years old
Switzerland	Reimbursed access – patients < 20 years old, including type IIIa
Ukraine	Dossier to be submitted in Q2 2019
Middle East	
Israel	Reimbursed access – all patients
Kuwait	Pricing negotiations under way; a named-patient programme in place for patients with SMA type I
Qatar	Pricing negotiations under way; a named-patient programme in place for patients with SMA type I
Saudi Arabia	Pricing negotiations under way; a named-patient programme in place for patients with SMA type I
Turkey	Reimbursed access – all patients
UAE	Pricing negotiations under way; a named-patient programme in place for patients with SMA type I
Asia and Australasia	
Australia	Reimbursed access – patients below 18 years old
China	Approval/HTA under way
Hong Kong	Reimbursed access – all patients
Japan	Reimbursed access – all patients
Korea	Reimbursed access (details missing)
New Zealand	Pricing negotiations under way; Biogen's humanitarian programme in place for patients with SMA type I
North America	
Canada	Québec: Reimbursed access – all patients Other provinces: Reimbursed access for babies with SMA type I below 6 months (subject to clinical criteria); a new HTA under way for other patients; Biogen's humanitarian programme in place for a limited number of most urgent cases of SMA type II and III
United States	Reimbursed access as approved by individual insurance providers (those rejected may access the treatment via Biogen's humanitarian programme)
South America	
Brazil	
Argentina	

Stop or Step Up?

Track record

Know what has been done - what have we spent on and why?

Know what has to be done - where should we spend/invest on and why?

Benchmark

Know how actual performance compares with performance norms

Fill the gap

Know what remains to be done – how are we going to improve?

Action (OTIF)

Identify & implement corrections – make the change

Impact

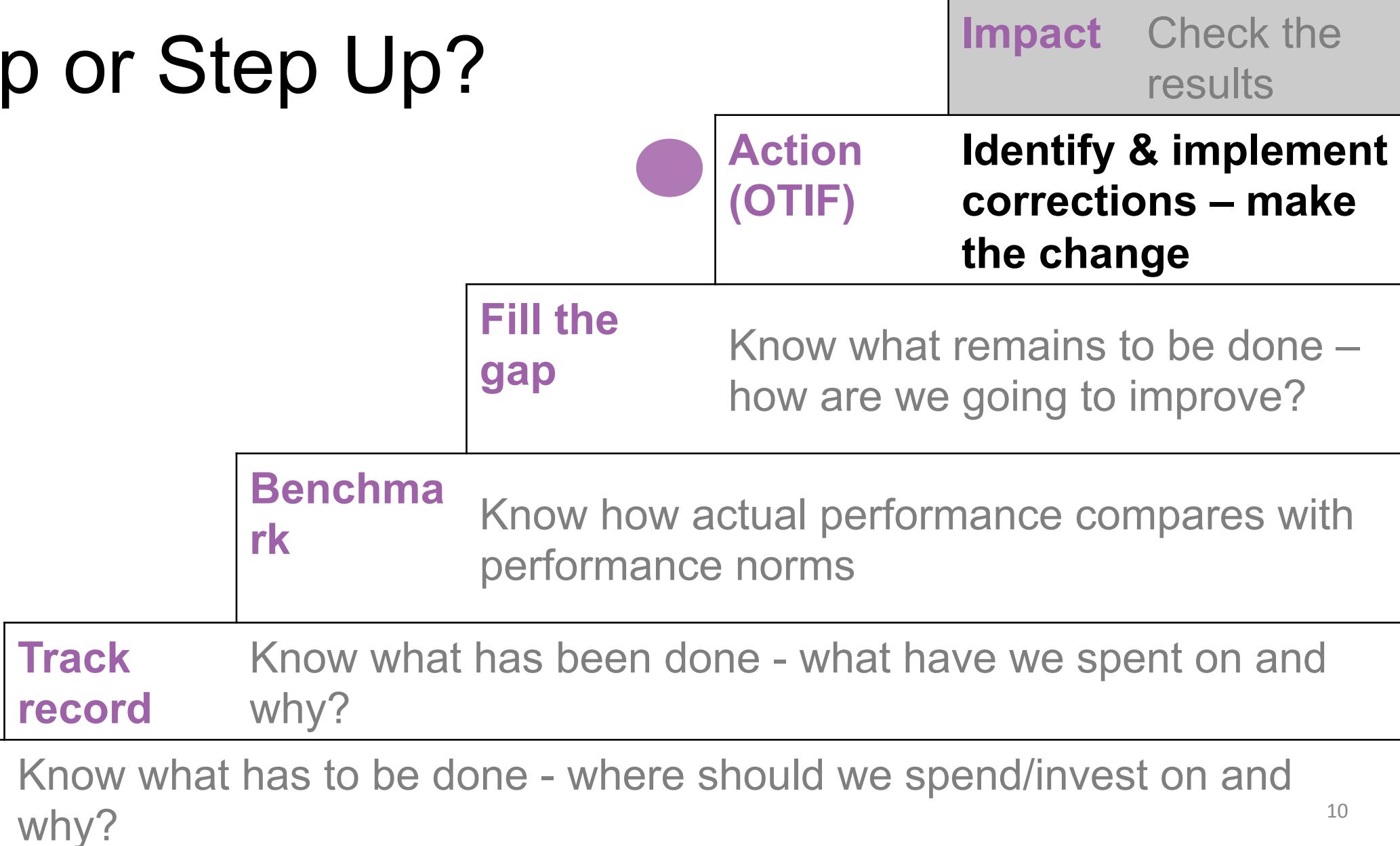
Check the results

Cost control and the right to health



Better that we...	We could Start to/ Continue to...	We should Stop...
Negotiate smartly To get more from what we spend	Work together towards common goals e.g. BeNeLuxA	

Stop or Step Up?

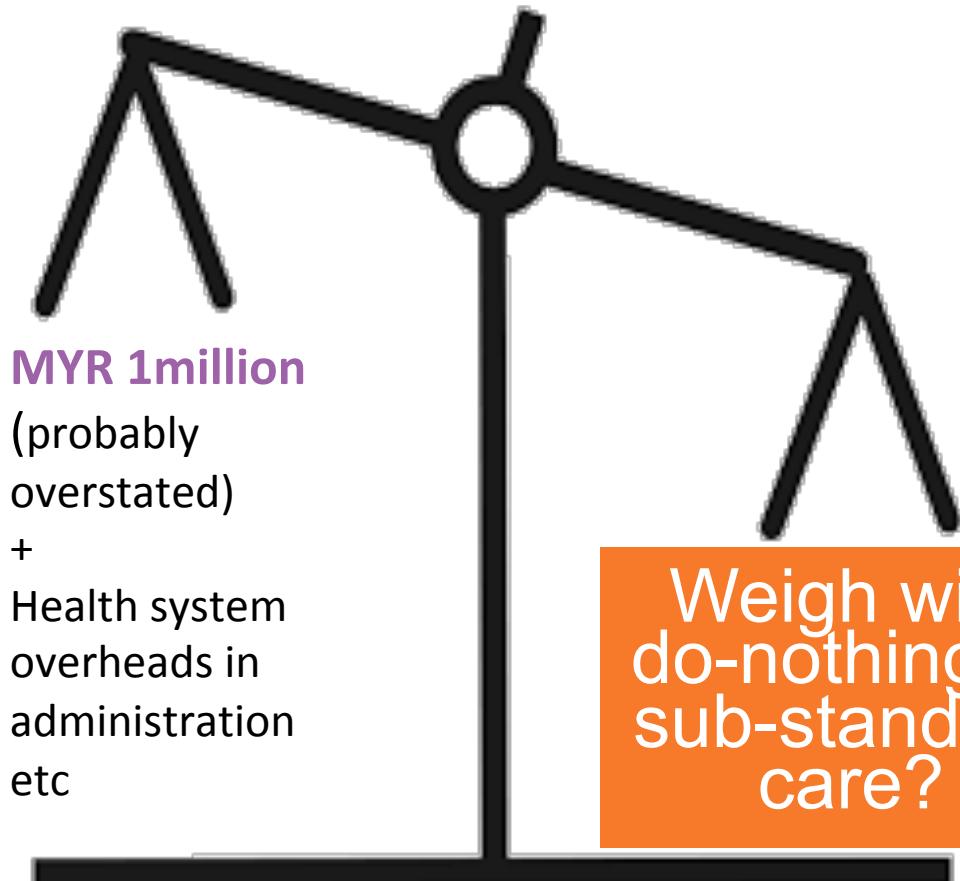


Decisions & Priorities

Spend	
On	Payback example

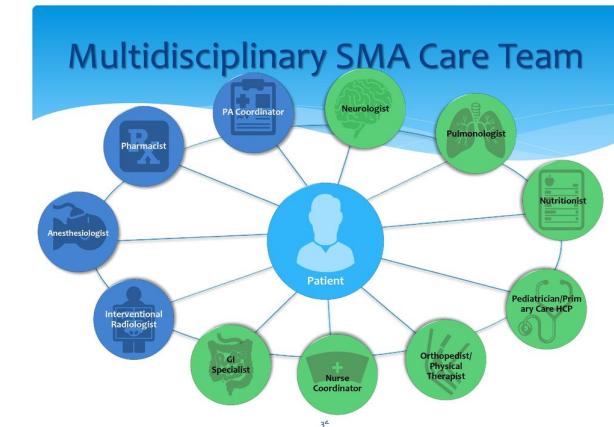
Is it just about the numbers?

Proper “business case”



Reduced or Eliminated Cost of

- Multiple, and long duration, critical care hospitalisations
- Regular consultations with specialists
- Demands of family and care coordination
- MEI machines
- BiPAP machines
- Body brace
- Hand wrist brace
- Ankle foot orthotics
- Scoliosis surgery
- PEG
- Complications
- Specialised nutrition
- Home renovations
- Transfer systems
- Seating systems
- Car modifications
- Care for care-givers
- Various assistive devices
- Etc



Add the Gains

- Functional and clinical and real world
- Cognitively able and high economic and societal value
- Patients + Care-givers

Stop or Step Up?

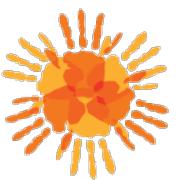
Impact	Check the results
Action (OTIF)	Identify & implement corrections – make the change
Fill the gap	Know what remains to be done – how are we going to improve?
Benchmark	Know how actual performance compares with performance norms
Track record	Know what has been done - what have we spent on and why?
Equity	Know what has to be done - where should we spend/invest on and why?

Costs or Investments?



You can make
a BIG impact

Thank you! ☺



MAKE A DONATION



Join us on this **SMALL** mission

and make a **BIG** difference



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