

A stylized white silhouette of a woman's head and hand is set against a blue background. The woman's head is on the left, facing right, with her eyes closed. Her hand is on the right, palm up, as if holding something. The background is a solid blue color.

Patient organisations - standing and funding

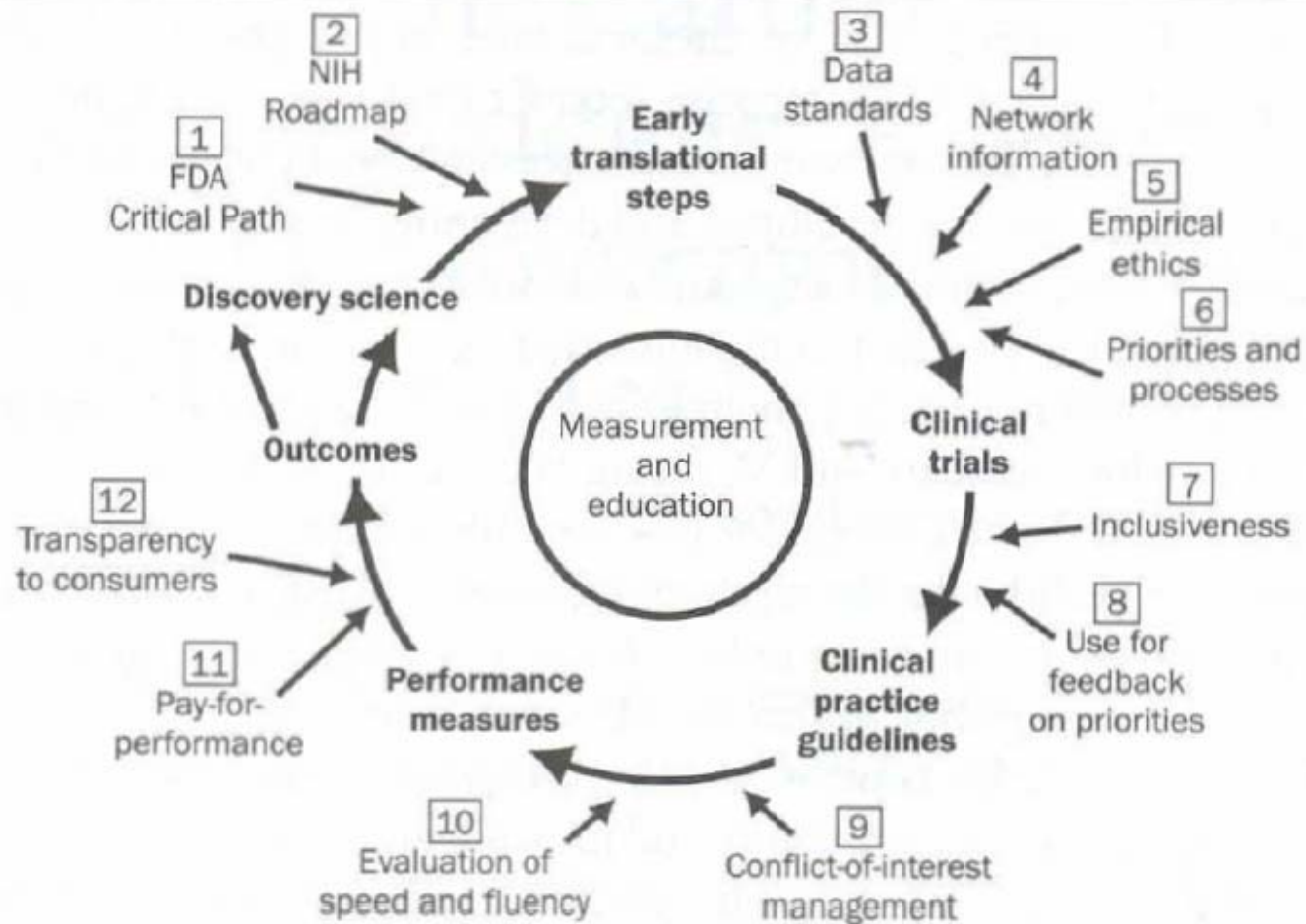
Richard Bergström
Director General
Swedish Association of the
Pharmaceutical Industry

Agenda

- The role of patients
- The role of patient organisations
- Relations with governments and industry
- Some recommendations



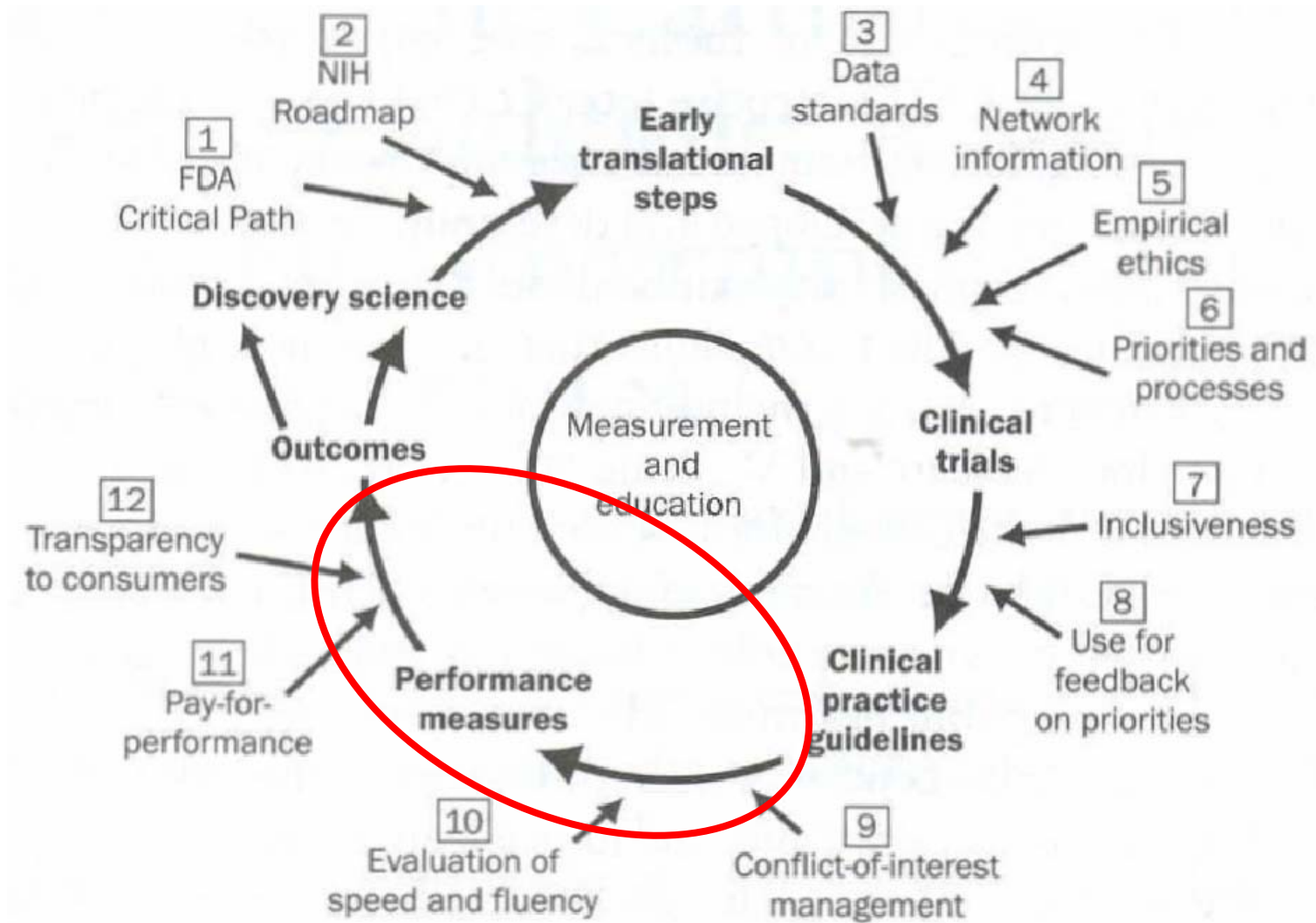
EXHIBIT 1 The Cycle Of Quality: Twelve Steps



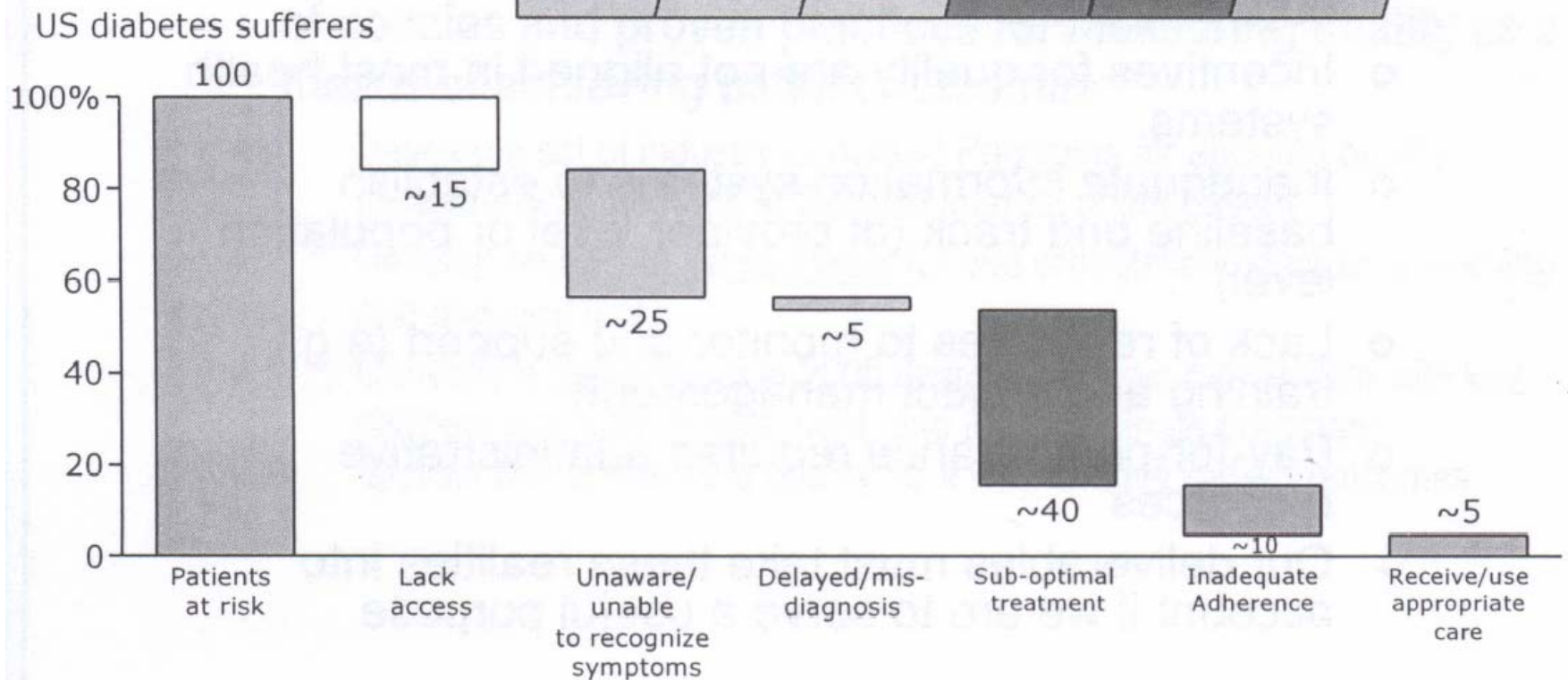
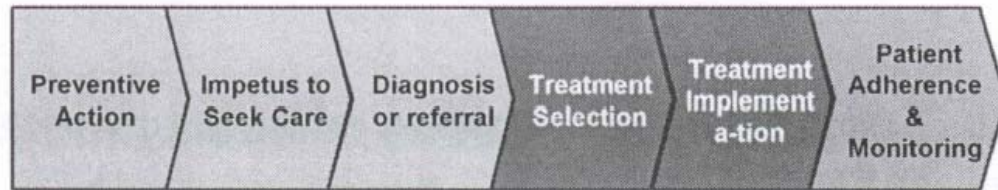
SOURCE: Adapted with permission from R. Califf et al., "Integrating Quality into the Cycle of Therapeutic Development," *Journal of the American College of Cardiology* 40, no. 11 (2002): 1895-1901.



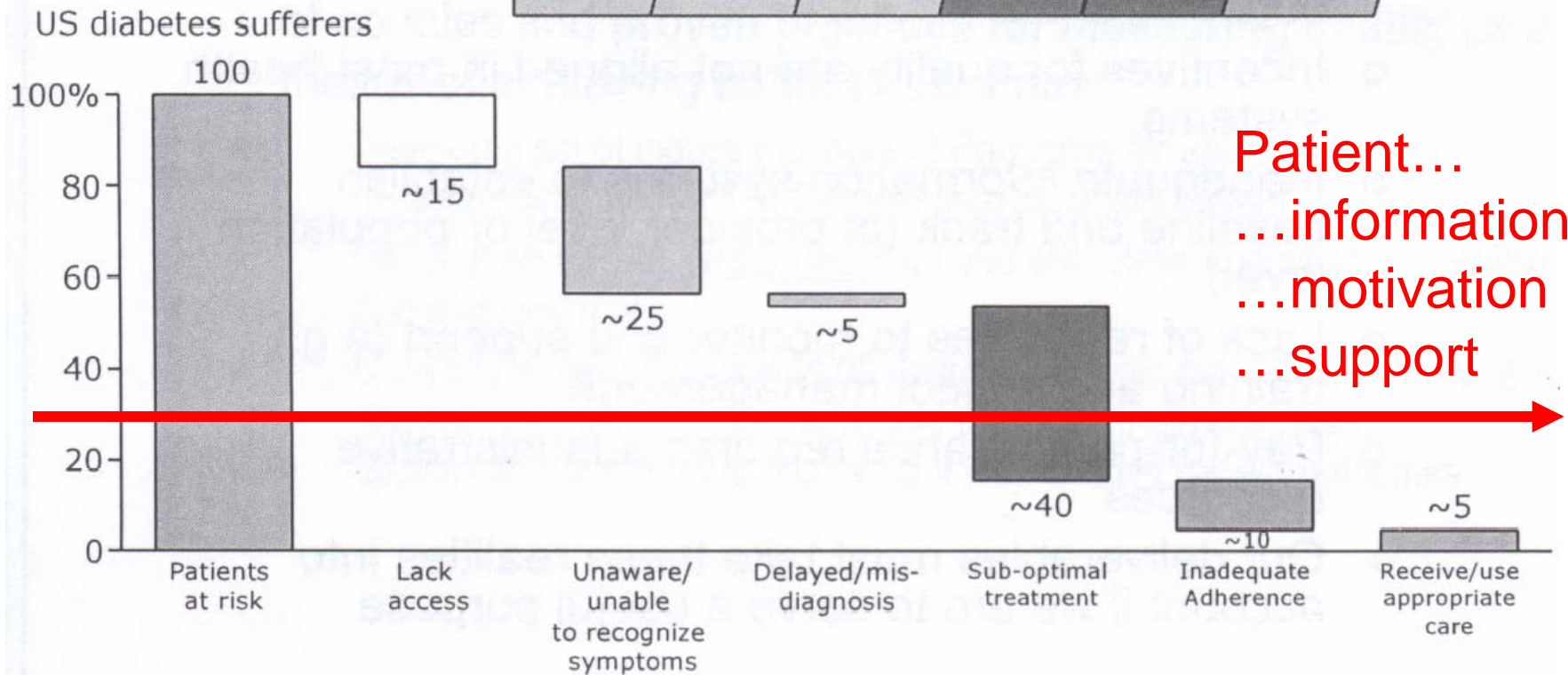
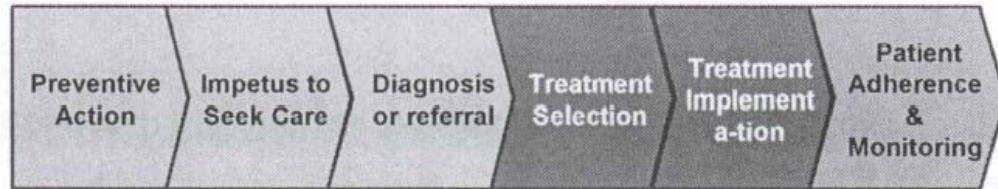
"Lost in translation"



Quality “Leaks” - Diabetes



Quality “Leaks” - Diabetes



Towards high performing health systems

Top-down

- Implementation of evidence-based medicine
- From DRGs to pay-for-performance (P4P)
- Full accountability

”Consumer pressure”

- Patients can choose
- Full transparency of results and performance
- Patients are informed
- Patients will ”vote with their feet” and exert pressure



The industry can contribute - the Swedish experience

- FASS compendium + Patient-FASS
- FASS.se (>4 million visits per month)
 - Statutory information
 - Disease information
 - Research information
 - Environmental classification
 - Educational programs (drugs in the elderly)
- Quality seal (>100 company sites)
- Corporate patient support
 - Leaflets for patients and relatives
 - Compliance programs
 - Websites for disease-awareness
 -

FASS.se 

Källan till kunskap om läkemedel



Examples of company web-sites

www.abilify.se

www.allergi.nu

www.astma.nu

www.cancer.nu

www.cancer.roche.se

www.cozaar.se

www.detrusitol.se

www.enbrel.se

www.epilepsiguiden.se

www.flu.se

www.fosamax.se

www.klimakteriet.nu

www.ms-portalen.se

www.plavix.se

www.psoriasisguiden.se

www.psykiatriinfo.se

www.remicade.nu

www.schizofreniskolan.se

www.stroke.nu

www.xalatan.se



Example: Project with Swedish Reumatism Association

Vi vill ha lättöppnat!

Queremos que sean fáciles de abrir!

We want easily opened!

Haluamme helposti avattavia!

Kolay açılmasını istiyoruz!

Želimo da se lako otvara!

حتفلا لهس هديرن!

میهاوخ یم دنوش یم زاب ناسآ هک ییاه یدنب هتسب ام!



Self-regulation can work

- Evaluation by Swedish MPA in November 2006: self-regulation, in conjunction with regulation, has added value
 - Can go further than legislation (and constitution)
 - Additional sanctions (even when activities are stopped)
 - Competitors watch each other
 - Preventive measures and pre-vetting possible
- Good experience in many countries
- Problem (e.g. with relations with doctors) has rather been with the ethical rules themselves, not the system of oversight and sanctions
- Multi-stakeholder initiatives particularly interesting



Patient organisations

- Increasingly important as advocates for patients
- Must remain independent and credible
- Should not be entirely funded by either government or industry.
- Policy implications
 - Industry sponsoring only for projects of common interest (no unconditional grants)
 - Full transparency
- National rule and database in place in Sweden since 2006
- Recent initiative by GSK – likely to be followed



Whether we like it or not...

**patient organisations
stand and fall with their funding**

- in many ways....

