



**International Consortium for Health
Outcomes Measurement**

COMET V Meeting

20th May 2015

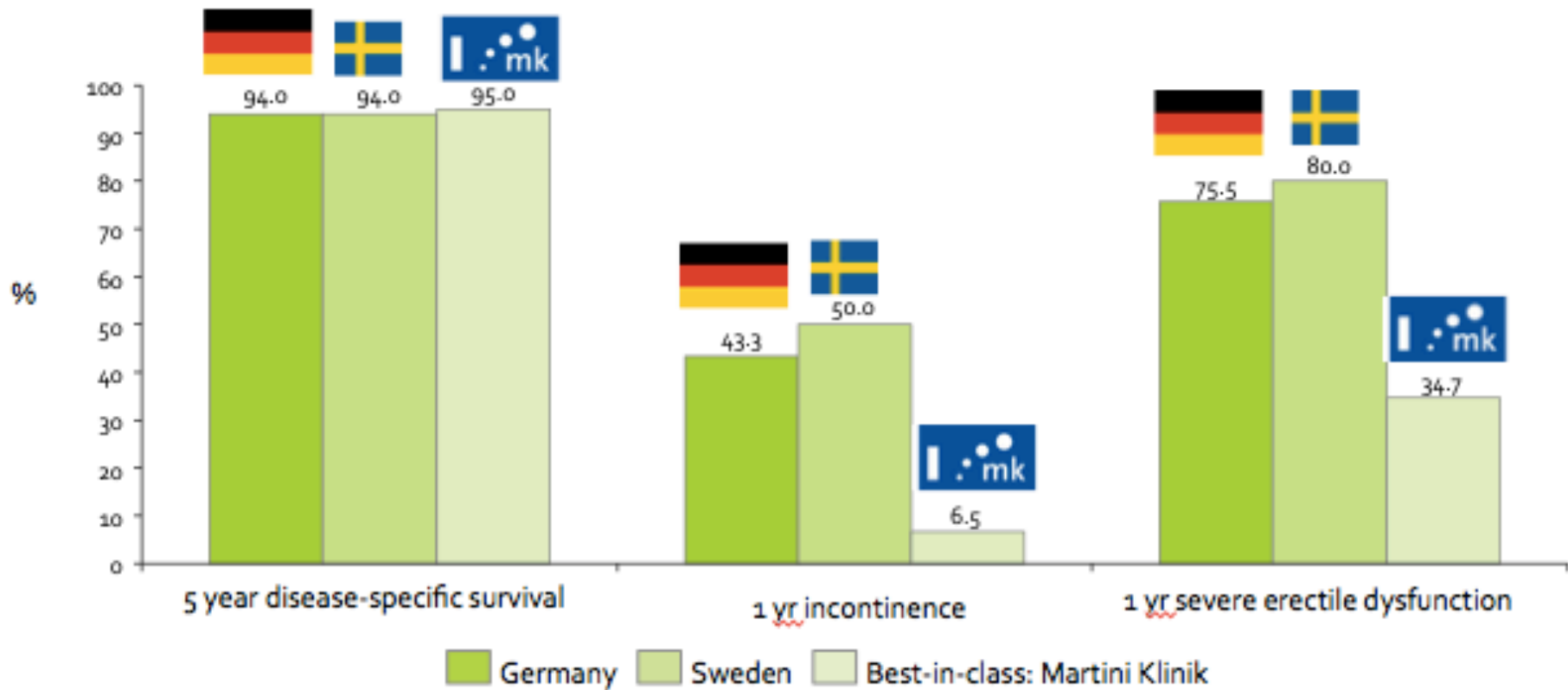
Table of contents

Why ICHOM?

What we do

Implementation and benchmarking

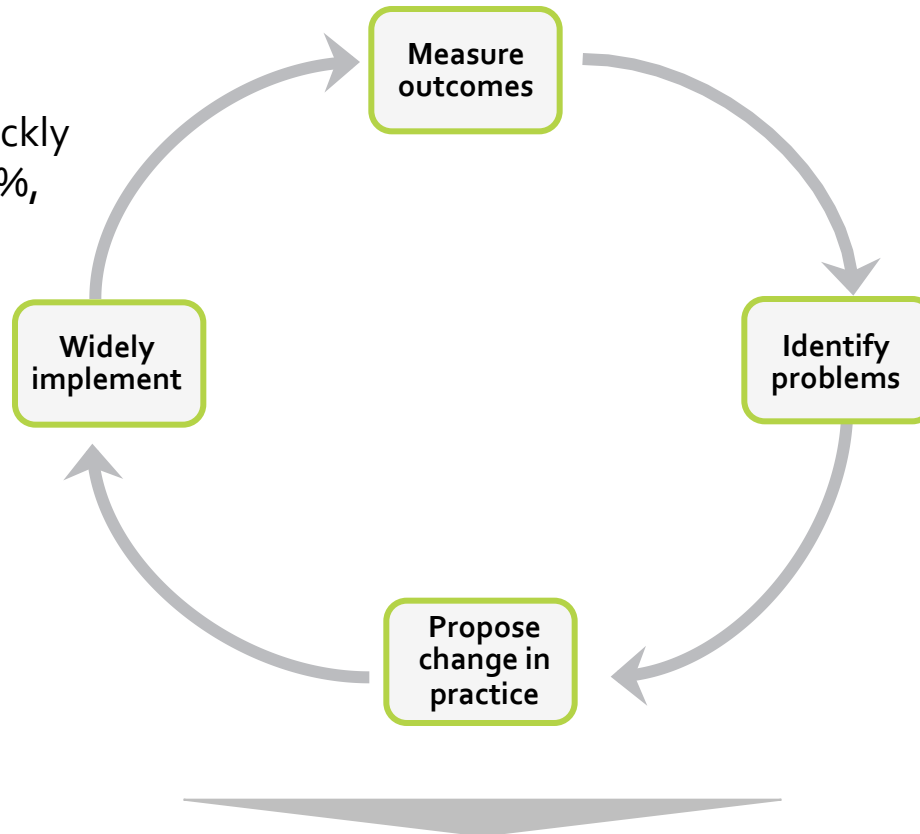
Variations in prostate cancer outcomes



Swedish data rough estimates from graphs; Source: National quality report for the year of diagnosis 2012 from the National Prostate Cancer Register (NPCR) Sweden, Martini Klinik, BARMER GEK Report Krankenhaus 2012, Patient-reported outcomes (EORTC-PSM), 1 year after treatment, 2010

A complete cycle of measuring outcomes that matter most led to better care for patients

One-week urinary continence rates quickly rose from 50% to 70%, and one-year from 94.7% to 96.9%.



Outcome data analysed and discussed every 6 months to detect differences.

Peer based learning from the best physicians.

A surgical technique demonstrated better urinary continence outcomes than the current method

A structured forum for discussing outcome variations along with peer support allowed for rapid spread of best practices

The lack of outcome measurements that represent what truly matters most to patients is a global barrier to driving health care improvement

Problem

- 1 Paucity of outcomes data beyond basic mortality measures
- 2 Where available, outcomes are hard to compare and not standardized
- 3 Outcomes are often not patient-focused
- 4 Large focus on process measures

Result

- Lack of information for patients and providers on whether what we do works
- Slow pace of change and inability to learn from others
- Success not defined from patient perspective
- Assumption that changing processes improves outcomes for patients

ICHOM was formed to drive the industry towards value-based health care by defining global outcome standards

ICHOM's three founders...



...launched ICHOM as a nonprofit

- Independent 501(c)3 organization
- Idealistic and ambitious goals
- Global focus
- Engages diverse stakeholders



Our mission:

*Unlock the potential of Value-Based Health Care by **defining global standard sets of outcome measures that really matter to patients** for the most relevant medical conditions and by **driving adoption and reporting** of these measures worldwide.*

ICHOM plays several roles along the journey that will enable Value-Based Health Care: our Strategic Agenda

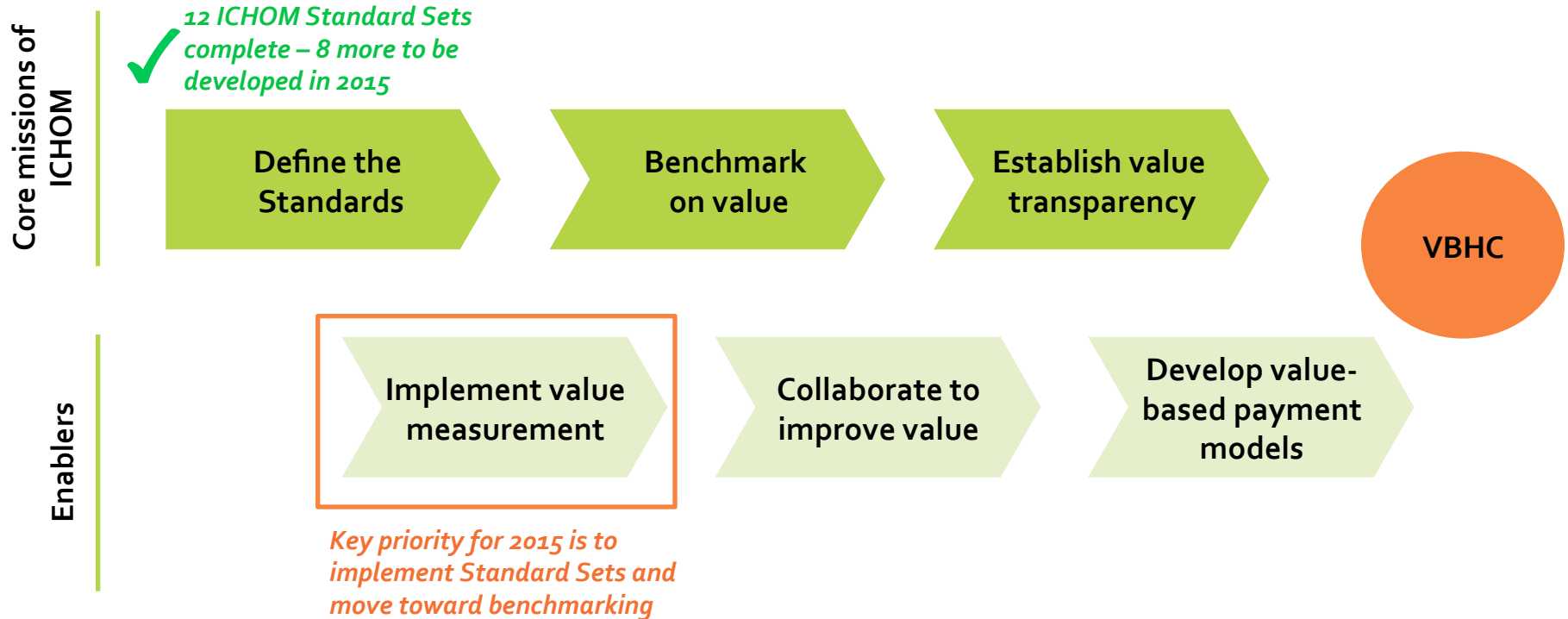


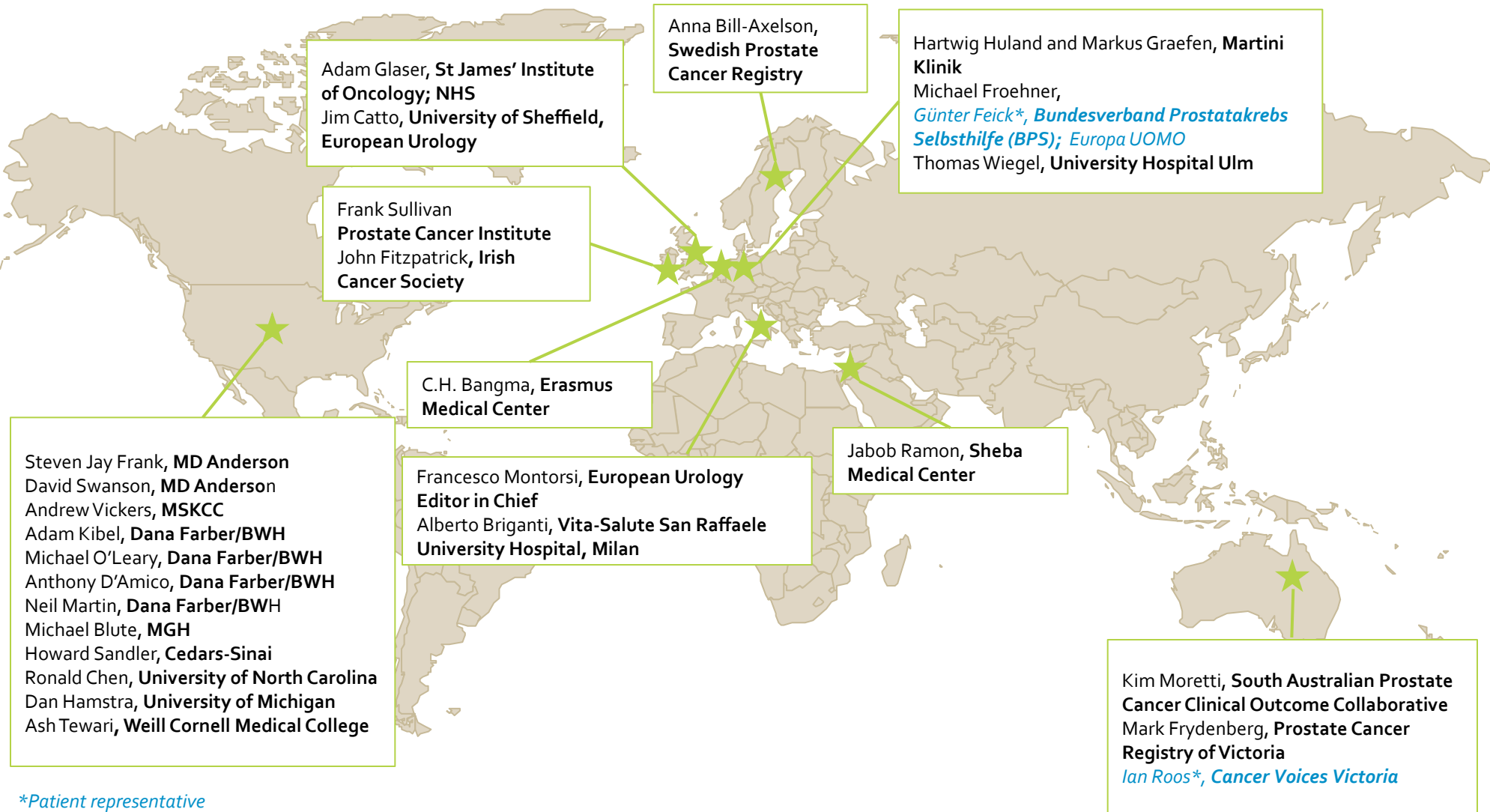
Table of contents

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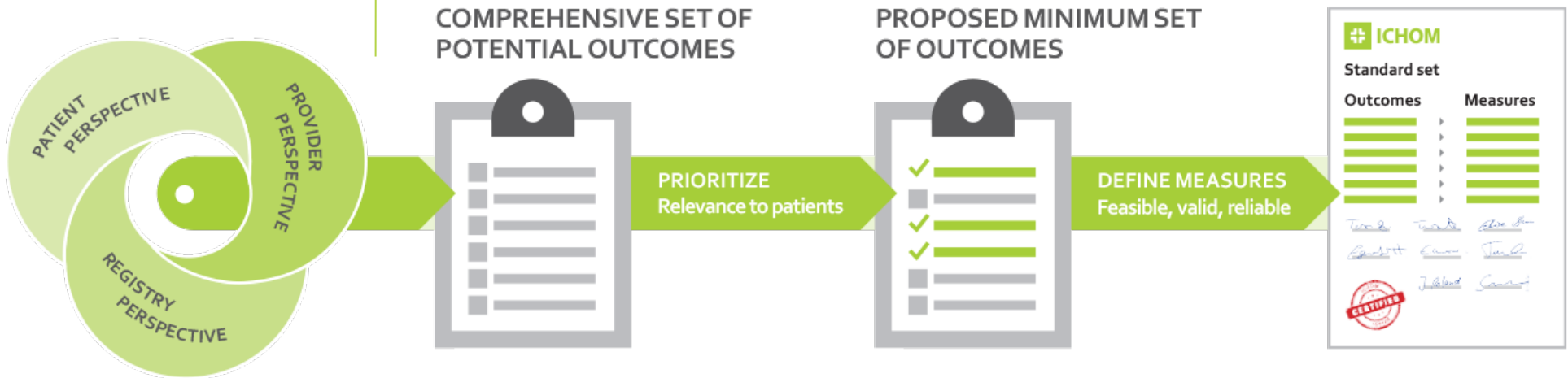
Implementation and benchmarking

International leaders in the field and patients have helped to develop all of ICHOM's Standard Sets e.g. Localised Prostate Cancer



ICHOM has developed a Standard Set methodology

Begins with a systematic review of the literature:
Outcomes measured in routine clinical practice and outcomes reported in studies looking at the effectiveness of management.



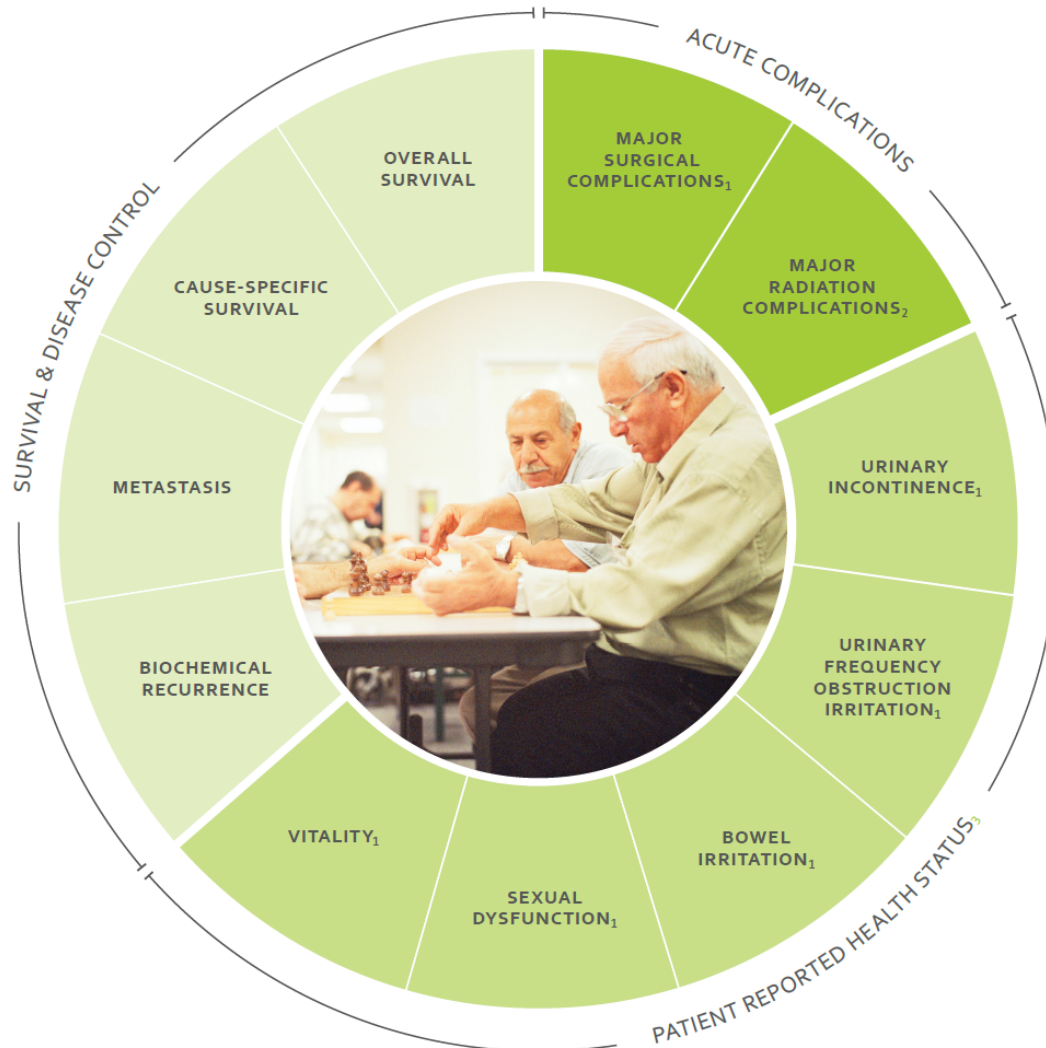
We have already developed 12 Standard Sets, covering 35% of the disease burden



2015 targets

- Dementia
- Frail elderly
- Heart Failure
- Pregnancy and childbirth
- Breast cancer
- Colon cancer
- Brain tumors
- Inflammatory bowel disease

ICHOM Standard Set for Localized Prostate Cancer: Outcomes



Treatment approaches covered

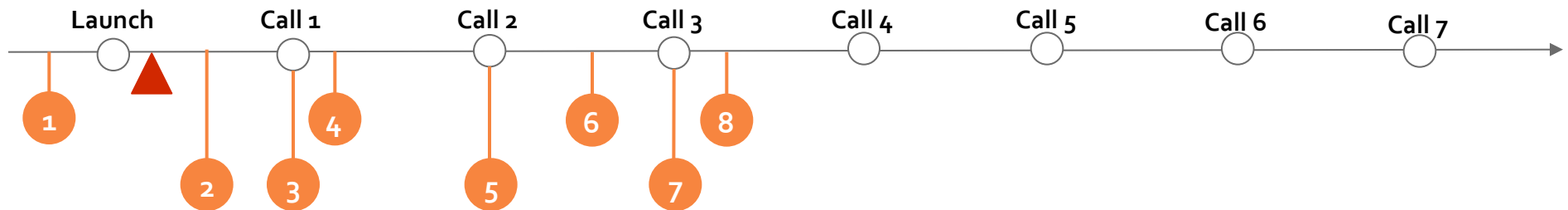
- Watchful waiting
- Active surveillance
- Prostatectomy
- External beam radiation therapy
- Brachytherapy
- Androgen Deprivation Treatment
- Other



A "Reference Guide" contains all the details to measure in a standard way the outcomes and case mix factors recommended (see [here](#))

© 2013 ICHOM. All rights reserved. When using this Standard Set of outcomes, or quoting therefrom, in any way, we solely require that you always make a reference to ICHOM as the source so that this organization can continue its work to define Standard Sets.

We have recently updated the standard set methodology



- 1. Recruit two patients from four patient charities**
 - Diversity of age, disease subtype, treatment type and time since intervention.
- 2. Focus Group VC**
- 3. Call 1: Outcome domains**
 - Feed suggested domains into discussion

- 4. 3 Delphi rounds with WG and wider network of patient advocacy groups**
 - Contains proposed outcome domains
 - Ranking using the GRADE scale
- 5. Call 2: Outcome definitions**
- 6. WG survey on outcome definitions**
- 7. Call 3: Outcomes wrap-up**

8. Patient networks and other stakeholders will be invited to review final Standard Set as part of Open Review Period (up until Call 6)

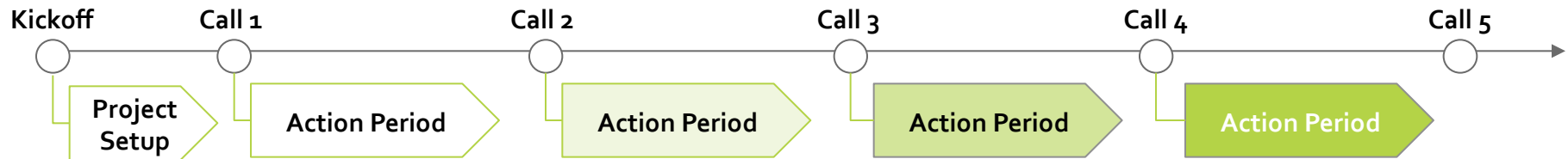
Table of contents

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Implementation and benchmarking

An implementation community is a structured framework that enables members to measure, learn, and compare outcomes



Community selection

~ 5 organisations for initial implementation community group

Community model

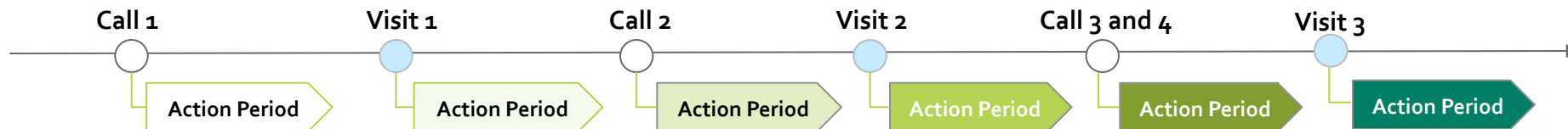
Monthly WebEx (or similar) calls – driven by ICHOM

- Part I: update on progress
- Part II: guidance on next steps

Members

“Action Period” between calls — participants aim to **complete specific tasks** related to implementation that were discussed during part II of the most recent call

Capacity building is targeted on-site support at key implementation milestones along with 1:1 remote support



Engagement model

Aim: Assist in measuring a full Standard Set, enabling independent replication of implementation process in other Medical Conditions

Hybrid engagement model:

- Three on site visits each lasting
- Four remote check ins to support key implementation actions

“**Action Period**” — between each engagement whereby site **strive to achieve major milestones** related to implementation as specified in project plan.

ICHOM role

Calls

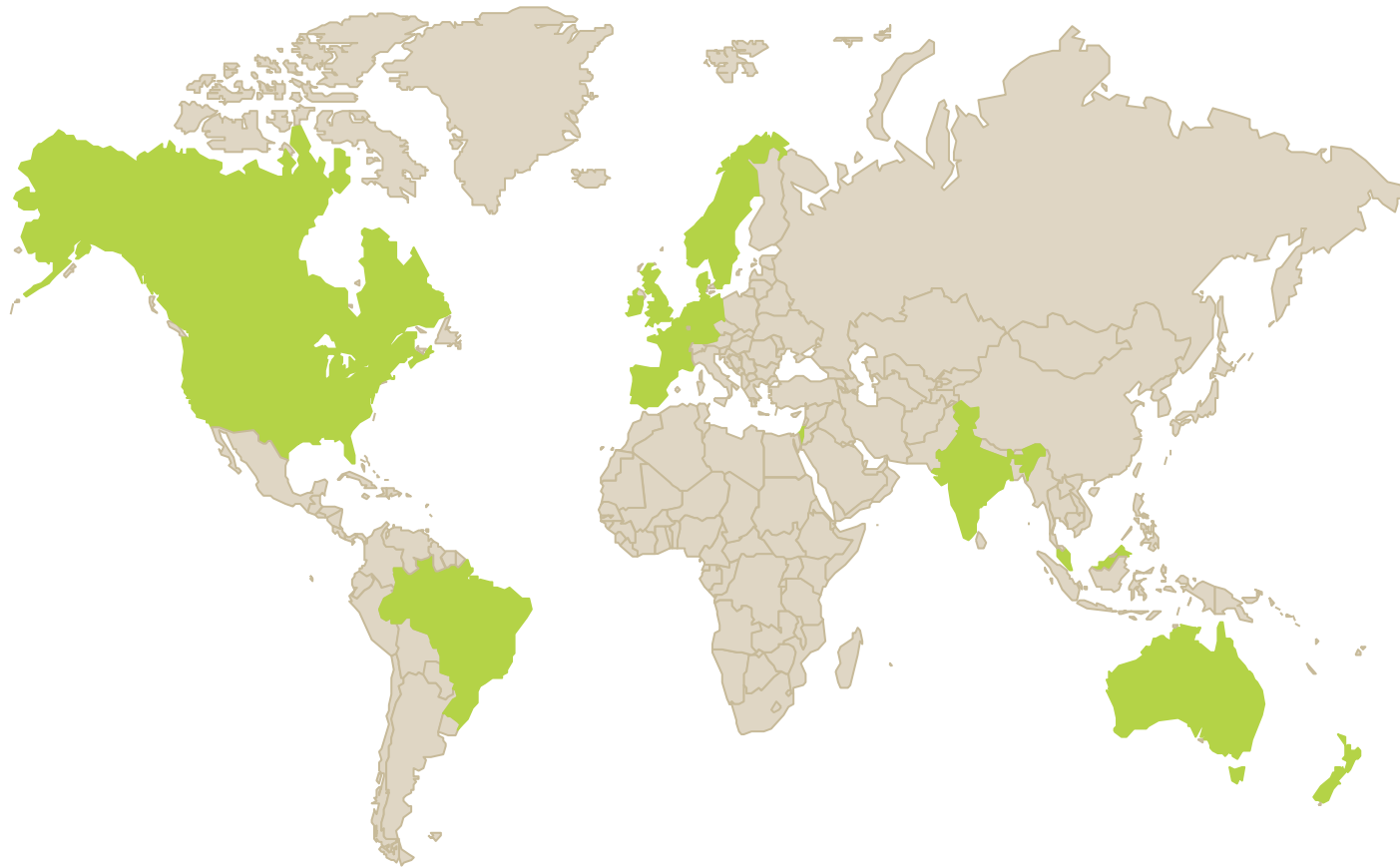
- Schedule check-ins and organize agendas
- Facilitate discussions with expert contacts to cover key topics and answer questions
- Debrief and thought partnership on challenges

Site visits

- Engage with Clinicians, project team, IT, Oversee deployment of e-PROM
- Facilitate QI method set-up (e.g., run first PDSA cycle)
- Potential for case study/ vid-doc to document journey

Implementation progress

13 nat'l registries + ~60 institutions are already measuring or intend to measure ICHOM Standard Sets



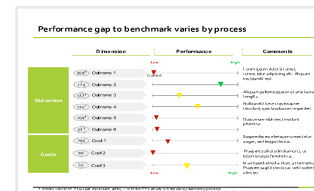
ICHOM launching global comparisons benchmarking program

First benchmarks available in 2016

Objectives of Global Comparisons project

- 1 Pool health outcomes data from 10-15 leading provider organizations – 2 conditions for pilot**
 - Localized prostate cancer
 - Cleft lip and palate
- 2 Risk-adjust raw data and organize comparisons on key indicators**
 - *E.g.* for LPC: level of incontinence, impotence
- 3 Provide individual – and confidential – reporting to participating organizations**

Key deliverables



Individual reports for organisations



Publication: key learnings from comparisons

Acknowledgements

- OMERACT - Handbook 2014
- COMET guidance
- James Lind Alliance Guidebook
- NHS Involve
- Canadian Institute of Health Research – Patient Engagement Framework, 2014
- MacLennan et al. (2015). A core outcome set for localised prostate cancer effectiveness trials: protocol for a systematic review of the literature and stakeholder involvement through interviews and a Delphi survey. *Trials*.