

ACNE CORE OUTCOMES RESEARCH NETWORK

Information for new members

11/2015



What is ACORN?

- Set up in July 2013 with funding from US National Institute for Health
- Mission
 - To develop a universally agreed set of core outcome measures for use in clinical efficacy studies
- Key people: Diane Thiboutot (PI), Jerry Tan, Alison Layton
- Principles:
 - Global representation
 - Stakeholder participation
 - Use of consensus-based methods
- Partners:
 - COUSIN – Cochrane Skin Group Core Outcome Set Initiative
 - COMET Initiative – Core Outcomes in Effectiveness Trials

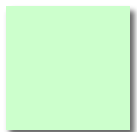
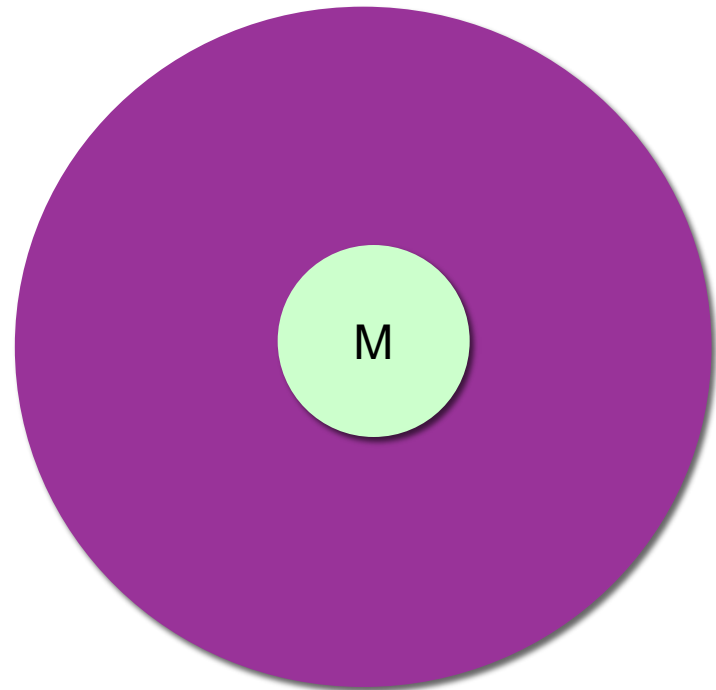
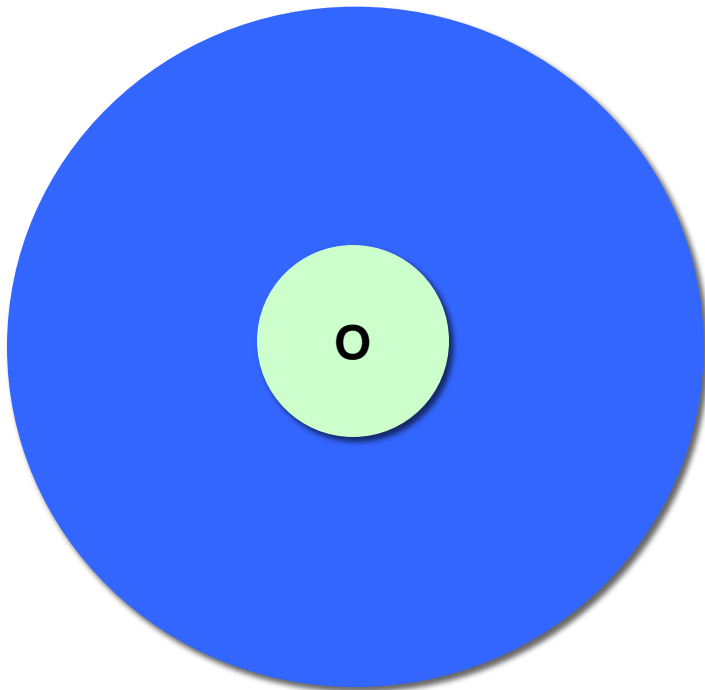
What is a core outcome measure set?

- A consensus agreed minimum set of validated outcome measures for use in all acne clinical trials
- Typically relate to efficacy and safety
- Easy to use
- Relevant to people with acne and those who provide treatment in any setting
- Universal adoption of the core outcome set permits valid comparison and pooling of data from individual trials

Implications

- Core outcomes should always be measured using the instrument/technique included in the core outcome set
- Core outcomes should always be reported in full
- When needed, other outcomes can be measured in addition to the core set

Concept of core sets of outcomes & measures



Core set – universally agreed and adopted

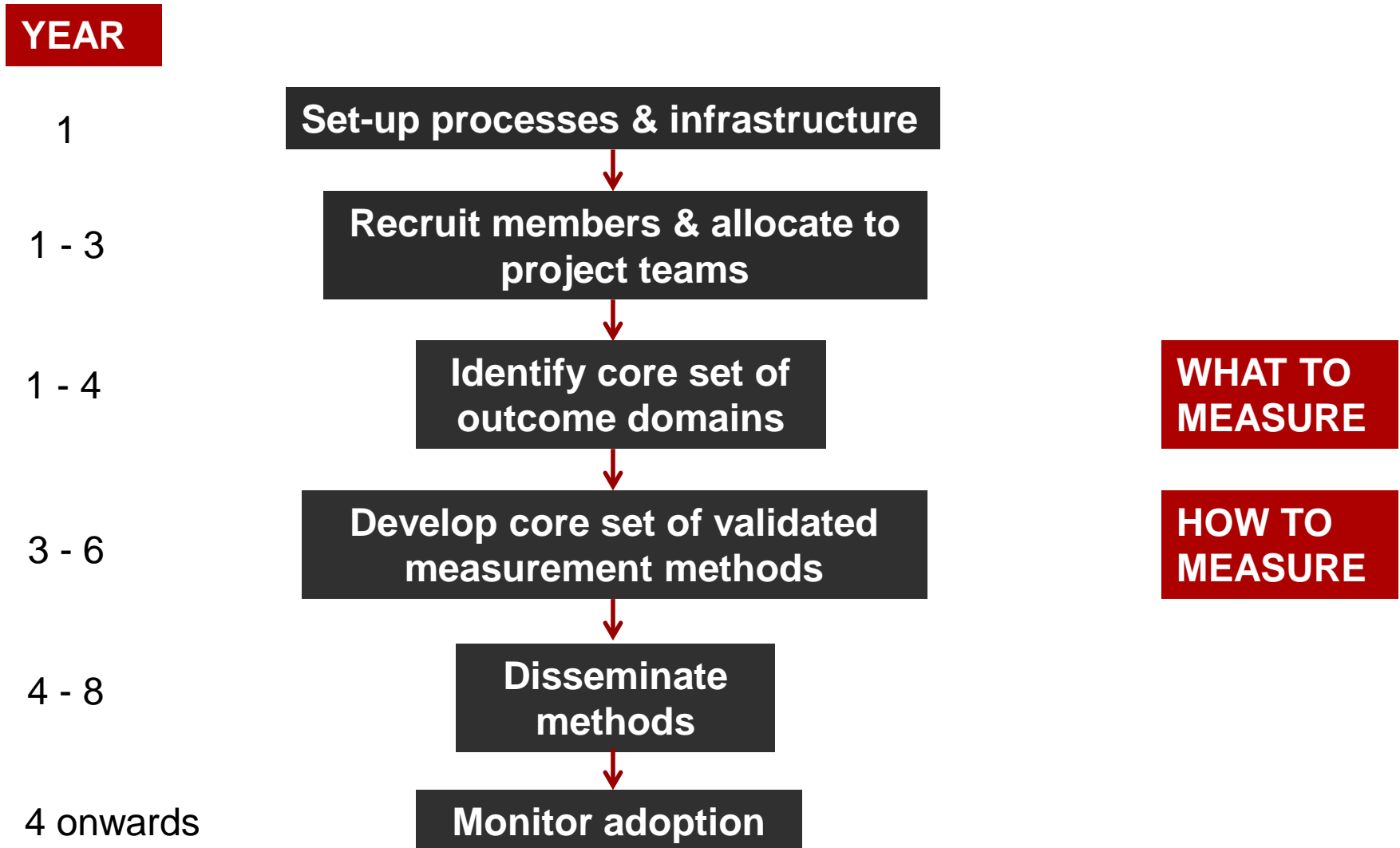


All possible outcomes – what is being measured



All available instruments – ways of measuring different outcomes

Timeline for development of core outcome set



ACORN groups



Group composition/organisation

- 4-8 members
- At least one patient
- At least one member of methods group
- Elected leader who liaises with management group

- Leader to draft one page mission statement
- Project groups to work from protocol drawn up by members – protocol to be reviewed externally by COUSIN and internally by management team

Group communications

- Schedule of telecons within and between groups (every 6-8 weeks)
- Leaders of each group to hold regular telecons with management team (every 4-6 months)
- LinkedIn for open discussions/consultations
- ACORN website for collection/dissemination of information
- Twitter for publicity

Stakeholders

- People with acne
- Health care professionals
- Acne researchers in industry and academia
- Clinical trial support staff in industry and academia
- Representatives of regulatory agencies
- Providers of clinical research services
- Dermatology journal editors

Additional team members:

- People with expertise in relevant methods
 - biomedical informatics
 - use of digital technologies to support research
 - evidence synthesis
 - critical appraisal
 - medical statistics
 - psychometrics

Why join ACORN?

- Much of the time, money and energy spent on acne clinical trials is wasted
 - Different outcomes are measured using different methods
 - Reporting standards are low
- Patient input into the identification of what to measure has been minimal
- ACORN gives people with acne, health care professionals and everyone involved in the conduct of clinical trials an equal voice
- Universal adoption of the core outcome set depends on universal agreement about what to measure and how to measure it
- A bigger more diverse team means faster progress!