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

1
Set-up processes & infrastructure

1 - 3
Recruit members & allocate to project teams

1 - 4
Identify core set of outcome domains

3 - 6
Develop core set of validated measurement methods

4 - 8
Disseminate methods

4 onwards
Monitor adoption
ACORN groups

- Systematic review support group
- Core domains identification group
- Harmonisation of lesion counting group
- Communications group
- Information management group
- Methods group
- Patient input group

Management team
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!