Survey To Assess Research Satisfaction at Stanford (STARS)
Stanford University

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Established in 1998
7 sites
1999 - Stanford
2009 - 77 total
Translational Research Center
- 12 sites
Current Projections

- Q1 2011
- Q2 2011
- Q3 2011
- Q4 2011
- Q1 2012
- Q2 2012

Legend:
- Restore Airway Surface Liquid
- Other
- Nutritional - GI Therapies
- CFTR Modulation
- Anti Inflammatory
- Anti-Infective
Background Information

- Seasoned research team
- Good reputation
- Mentors
- What’s our secret?
- How can we improve?
Success Hypothesis:
Participants enjoy their research experience
Why?

- Relationship
- Close follow up
- Easy access to the team
- Early access to drugs
- Altruism
- Money
Developed a questionnaire

- 28 questions
- 5 categories:
  - Overall Research Experience
  - Research Process
  - Research Procedures
  - Research Environment
  - RC Professionalism
- Several open ended questions
- General comments
Stanford Database Search:

- 330 Stanford CF patients
- 107 patients eligible to participate
  - 84 completed
  - 25 parent, 59 adolescent/adult
  - 23 unavailable
Overall Results:

Stanford Study Subjects:
- satisfied
- safe
- well cared for
- experience was worthwhile
Stanford Research “Repeat Offenders”

Distribution of Number of Studies

Mean = 4
Median = 3
How satisfied subject was with research experience correlated with repeated research participation

Spearman’s $\rho = 0.3$

$p=0.05$
Factors that Correlated the Strongest with Level of Satisfaction with Research Experience

- Time to consider participation
- No pressure felt during enrollment
- Adequately compensated
- Center fosters research awareness and participation
- Working with research coordinators as an incentive

All Spearman’s $\rho > 0.4$
$p < 0.001$
Factors also correlated with level of satisfaction but less strongly:

- Well cared for
- Worthwhile experience
- Adequately informed
- Questions addressed
- Thank you letter
- Studies were available quickly
- Visits accommodating
- Time well utilized
- Knowledgeable RC’s
Areas for Improvement

- Adequate compensation
  - Education of patients/families.

- Clinic staff to foster research participation
  - Continuing education of clinic staff.

- Studies to open for enrollment in a timely manner
  - Continue efforts to streamline contract/budget process.

- Some recruitment strategies found not helpful
  - Develop new recruitment strategies.
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