

# TRACE STUDY

## Transition to Adulthood with Cyber guide Evaluation

**The utilization, utility and impact of a Transition Coordinator and the Youth Kit<sup>®</sup> among adolescents with chronic health conditions as they transition to adulthood. A pilot study.**

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Funding provided by  
AFP Innovation Fund,  
HAHSO

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## BACKGROUND

- ineffective transition from pediatric to adult health care is a common problem associated with poor adherence and health outcomes
- little evidence exists about the effectiveness of transition services and supports
- need for shared health management tools that are system-wide rather than disease-specific

## OBJECTIVES

- to evaluate to what degree youth with a variety of chronic conditions will utilize the transition intervention prior to and during transition to adult care
- to determine perceived utility, and impact on self-determination and perception of care

## RECRUITMENT

- Recruitment goal is 30 participants (Oct '09 – Jun '10)
- Patients who are ~17 yrs old and/or will be discharged from various clinics to an adult health care provider
- Patients will be excluded if they are fully dependent in their daily functioning, self-care and communication

## INTERVENTIONS

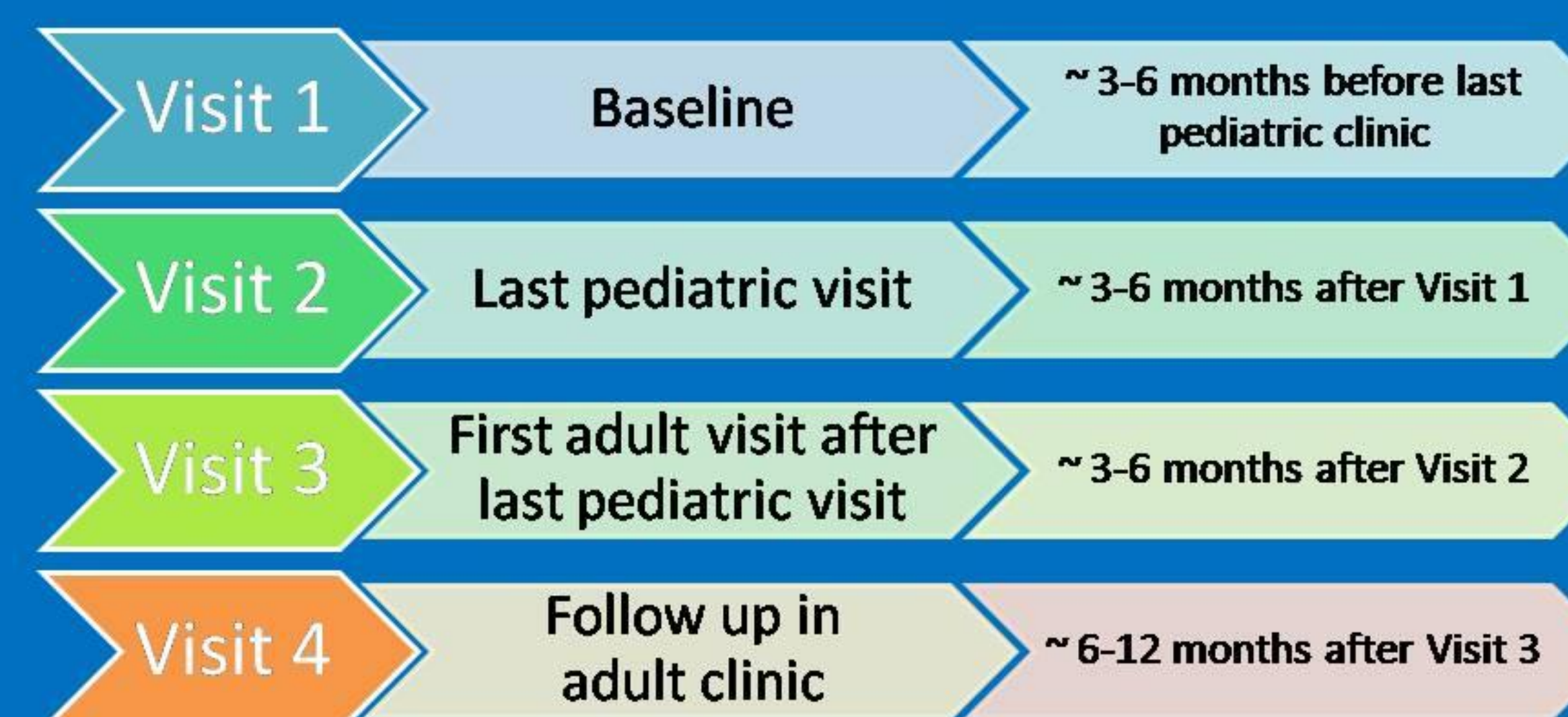
### TRACE the online Cyber guide

- TRACE and other study participants listen, provide support and encouragement, guide and help find resources and work towards personal goals
- Participants share goals and ask questions re taking charge of health care
- Chat about everyday experiences in taking charge of personal wellbeing, health and transition

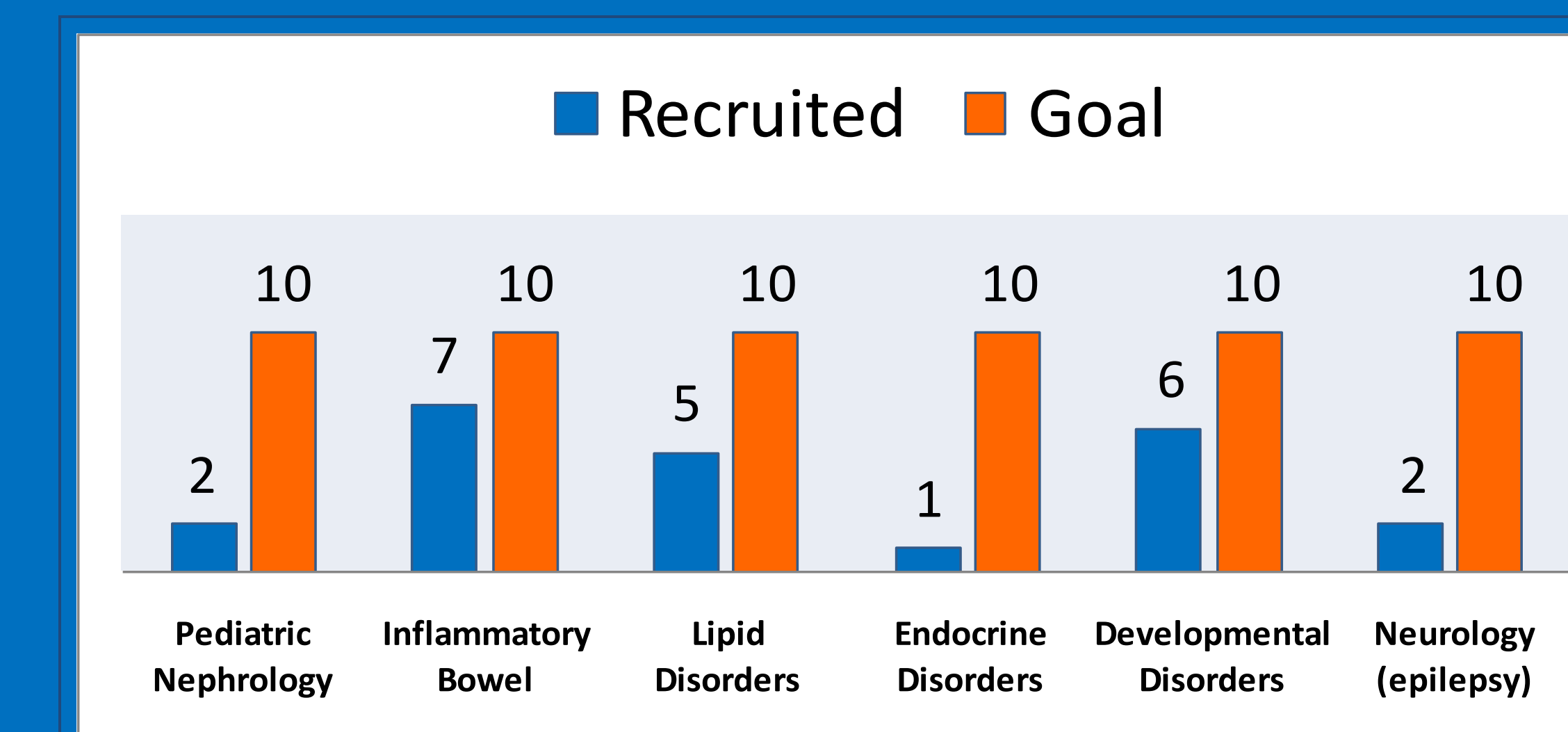
### Youth KIT<sup>®</sup> Workbook

- Helps identify the kind of information needed to go through the teenage years and make the transition to adulthood
- Keeps track of important information needed to do what you want, get what you want or to give to other people

## VISIT SCHEDULE



## PROGRESS TO DATE



## OUTCOMES

**Utilization** – completeness of Youth KIT<sup>®</sup> sections, logs of online activity with the Transition Coordinator and by self-reported frequency of use

**Utility** – questionnaire rating usefulness of components of the intervention. Focus group interviews to further explore the experiences of the participants

**Impact** on self-determination – questionnaires about perception and satisfaction with adult care [Giving Youth a Voice (GYV) and the Client Satisfaction Questionnaire (CSQ)]. Also success in achieving personal goals (COPM), clinic attendance and unplanned hospital visits.

## DATA ANALYSIS

- Utilization, utility and impact measures will be described using mean  $\pm$  SD, frequency distributions
- Qualitative research techniques will be used to analyze themes from the focus group transcripts