Adolescent Smoking Cessation Studies: Recruitment And Retention

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Office-based Teen Smoking Cessation Study Recruitment And Retention: *A Tale Of Two Cities*

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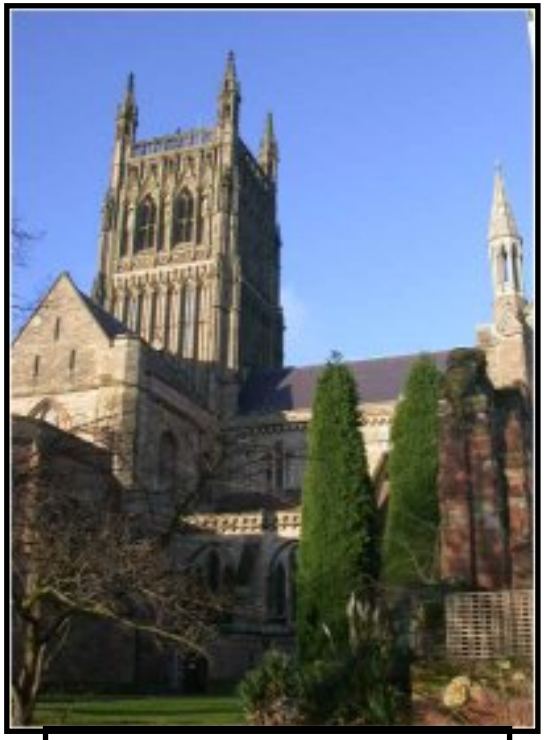
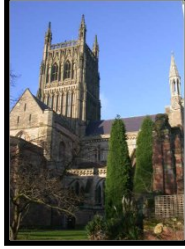


Worcester, Mass

Two NCI-funded randomized clinical trials approached teen smoking recruitment through office-based settings.

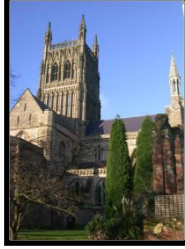


- The project at the University of Massachusetts utilized on-site strategies to recruit 2,711 teens at 8 practices into a study at well visits and acute visits.
- The project at the University of Rochester used clinician office referral for 8,385 teens at 101 practices after well visits.

Both studies had challenges and successes with recruitment and study retention.

"It was the best of times…. It was the worst of times."

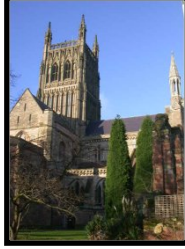
Recruitment and Retention – University of Massachusetts



The University of Massachusetts used a combination of onsite recruitment and proactive strategies (letters and phone calls) for engagement to a smoking prevention and cessation study. Approximately 90% of teens were recruited at well visits.

Though UMass did not meet recruitment goal of 600 smokers, retention was high with 99.6% and 99.2% of 262 smokers completing the 6 and 12 month surveys, respectively. Smokers at baseline were less likely to return questionnaires at 1 year, and the most common reason why teens stayed in the study was the financial incentive.

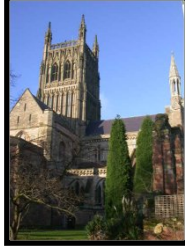
Recruitment and Retention – University of Rochester



The University of Rochester engaged both smoking and non-smoking teens at well visits to a generic "health study", with telephone screening (including assent and and parental consent by phone) and engagement of smokers for further follow-up. The “health study” approach allowed teens to be referred to study personnel without the need for office-based consenting. Study personnel called the teens within 48 hours.

Though UofR did not meet the recruitment goal of 1200 smokers 1,000 smokers completed the baseline questionnaire. Of the smokers, 81% were captured at the 3 month follow-up and 75% were captured at the 12 month follow-up.

The two sites held meetings to discuss successful strategies and barriers to recruit smokers into their respective studies



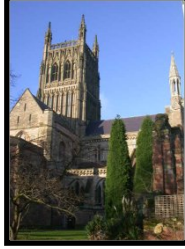
Problem-Solving Strategies:

- Obtained Supplement from NCI to study barriers and facilitators
- Site Visit to understand scope of projects, rationale for recruitment methods, “fresh eyes” to identify potential barriers

Strategies shared and discussed:

- Consent Forms and overall Consent Process
- Timing of approach
- Recruitment materials
- Recruitment process from start to finish

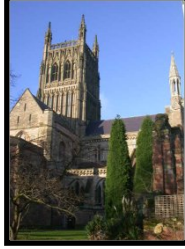
Lessons Learned



Project similarities:

- Adolescents seen in pediatric primary care offices for routine care – at “well visits”.
- Age range 13-17 (Pbert group), 14-18 (Ossip-Klein group)
- Office based physicians (*and Pas & NPs in UR practices*)
- Clinician advice + peer counseling (UMass = live, UR = quitline and web-chats)
- For adjunct intervention, UMass proactive, UR reactive.
- Both use on-site clinician training on 5A’s model.
- Both use 6 & 12 month Provider follow-up and 12 month Adolescent follow-up.

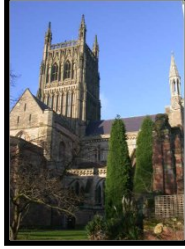
Lessons Learned



Project differences:

- UMass had 8 practices, UR had 100.
- UMass recruited on-site in pediatric offices with RA's, Physicians and Peer Counselors intervened on-site.
- UR recruited via office staff referral, and intervened via phone, mailings, and WATI (Web Assisted Tobacco Intervention.
- UMass addressed both prevention and cessation, recruiting all teens regardless of smoking status.
- UMass proactive adjuncts, UR reactive.

Lessons Learned



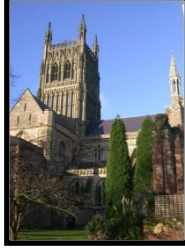
Both studies struggled to meet recruitment goals.

Why did we have problems recruiting at well visits?

- Teens not reporting or misreporting smoking?
- Not accessing smokers in office practices
  - Smoking adolescents not coming in for well visits?
  - Being seen in schools?
- Truly lower numbers of adolescent smokers than expected.
  - UMASS thought 25%
  - Rochester thought 29%

Note: Observed teen smoking rates are as low as 11-15% in both studies, smokers were defined as having a cigarette (at least a puff) in the last 30 days.

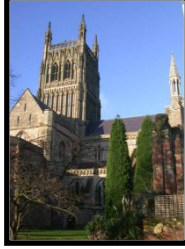
Low rates of smokers presenting for office visits may be explained by multiple causes



TRUE REPORT: There are "truly" lower numbers of smokers in the practice.

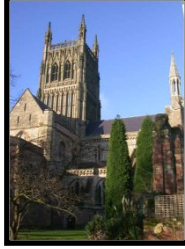
- Data suggest that smoking rates among teens from higher SES families are lower than for teens from lower SES families (Lowry et al, 1996; Harrell et al, 1998). It is possible that teens from high SES were more likely to have come in for well-visits.
- Good preventive practices may be delivered in target offices, hence they have lower percentages of smokers than expected based on population data.

Low rates of smokers presenting for office visits may be explained by multiple causes



- Good relationship between the practice and family could result in lower percentages of smokers. (Longevity and continuity of relationship important).
- Smokers may be more likely to be seen in schools and other health care settings.
- Do smokers have more acute visits? If true, will smokers be less likely to be seen for well-visits?
- Sports and camp trigger well visits. Smoking group not playing sports, not going to camp.

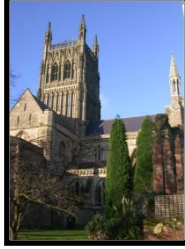
Low rates of smokers presenting for office visits may be explained by multiple causes



MISREPORT: Higher numbers of smokers exist, but they are "mis-reporting".

- Social Desirability (not disappoint family doc, avoid disapproval of provider, look healthy, etc.)
- Secondary Gains to “pass” physicals (make the team, etc.)
- Avoid Blame for smoking related illnesses (acute visits).
- Desire to focus on presenting concerns (cough, bronchitis).
- Mistrust of authority figure.
- Fear of parents finding out.
- Don't perceive selves as smokers.

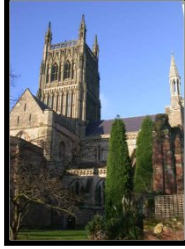
Low rates of smokers presenting for office visits may be explained by multiple causes



MISRECORD: Higher numbers of smokers exist in the practice, but researchers aren't accessing them.

- Not coming in for ANY visits (well or acute).
- Not covering/recruiting 5 days per week (UMass)
- Differences in Office Staff recruitment efforts (UR)
- Smokers are refusing participation
  - Rebellious
  - Fear of disclosure
  - Desire for privacy

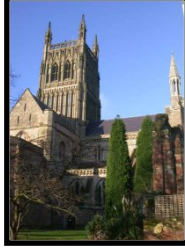
Lessons Learned



Consent Form As a “Barrier” to Recruitment:

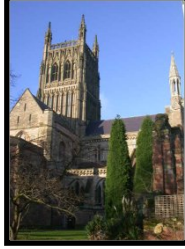
- •UMass considered possible changes in consent process for older teens.
- •UR met with some success by recruiting smoking and non-smoking teens (via Release Of Information forms) to a “health study” then enrolling (consenting) with a secondary process into an ongoing research study for just the smokers.
- •Future studies should attempt to simplify.
- •NCI should be petitioned to work with individual IRB's.

Recommendations



- Enhance Recruitment of Low SES:
  - Identify low SES catchment areas: housing prices, zip code, Medicaid analyses.
  - Letters to all low SES pts to be recruited for well visits.
  - Increase Research Assistant time in each site (UMass), e.g., 5 days per week.
  - Increase on-site and office service coordination (UR). This was problematic because of 100 total sites in study, so on-site was not feasible throughout the study. As a result of lessons learned from Umass, on-site recruitment was piloted in a low SES practice, with two RA's onsite. This met with limited success (office system itself was chaotic, hard to engage with). A specific trial with on-site recruitment in low SES settings could shed light on this.

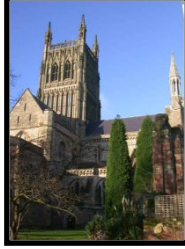
Lessons Learned



Quality and Consistency of Relationship between research team and practice site affects recruitment.

- It takes time to develop trust at the physician office sites, and trust increases the ability to recruit and promote a study.
  - Turnover (on research team, or in clinic) disrupts relationship-building, which then requires re-building
  - UMASS: Once the relationship was established between research and office staff, it was noted that office staff increasingly promoted the study (without specific encouragement to do so). They demonstrated more flexibility in allowing teens to participate in the study even if it affected clinic flow. Research staff had access to entire office)
  - UR: Office staff in engaged offices become more enthusiastic with time, and clinicians support ROI (referral) efforts. Research staff had access to entire office, including “secret” phone numbers.
  - BOTH: When research team is perceived as part of the clinic's staff, there is an increase in acceptance by teens and an increase in collaboration between practice and research. It is believed that this takes at least one month to develop.

More Lessons Learned



Current Manuscript with others:
Myra Myramoto, Cathy Backinger, Paul McDonald, Eric Moolchan, Debbie Ossip-Klein, Lori Pbert

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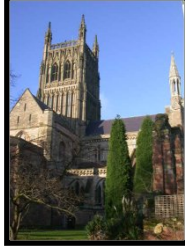
1. Recruit during well visits.

Pediatric and Family Medicine practices typically have preventive procedures targeted for well-visits. Take into consideration that practices tend to overestimate their numbers of smokers and well visits.

2. Determine and evaluate recruitment strategies for low SES adolescents.

Compared to higher SES, low SES adolescents smoke more, and go to physicians less often. Study results may not be generalizable unless this sub-population is more successfully recruited.

More Lessons Learned



3. Avoid project names with “stop smoking” focus.

In the 2 behavioral studies, project names were selected to avoid a negative stop smoking label to facilitate overall participation and introduce less bias from office staff who explained the study.

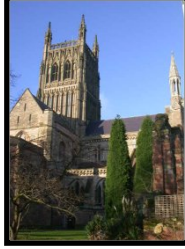
4. Offer Incentives.

Brand-name store gift cards with as little as a $5 value can be sent via mail, and charged to project only if used.

5. Establish strong working relationship with office staff.

Careful attention to the quality and consistency of the relationship between research staff and practice sites facilitates successful practice-based recruitment, promotion of the study by office staff, and unfettered opportunities for communication, such as access to all parts of the facility, and to private office telephone numbers.

More Lessons Learned



6. Recruit on-site when possible.

Office staff are not able to commit time and resources to recruitment details as can study personnel. Study staff can schedule various times to be located within the office setting to maximize recruitment.

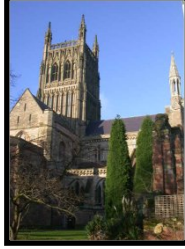
7. Build a continuing contact with practice.

Frequent visits, reminders, small gift incentives all serve to remind office staff of study details and progress.

8. Provide practices with feedback on their progress toward reaching recruitment goals.

Feedback can include total number of teens referred month-by-month, number of smokers receiving services, and overall study progress. This can be accomplished via monthly faxed newsletters or updates at staff meetings.

More Lessons Learned

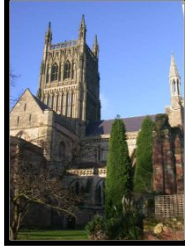


RETENTION

1. Collect extensive contact information to enhance follow-up.
   Collect information on head of household and three additional alternative contacts who could reach the adolescent. The addition of these survey items and resulting increase the length of the survey is justified by the higher retention rates achieved.

2. Use a multi-step procedure for follow-up data collection.
   For example, mail surveys in a brightly-colored envelope with a personalized letter from the research staff; if not received, make a follow-up and resend survey with 2nd personalized letter; if again not received, complete survey by phone.

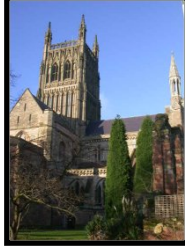
More Lessons Learned



RETENTION

3. Send personalized thank you notes following completion of each assessment.
   Positive reinforcement is a promising strategy with adolescent smokers, and increases cooperation with subsequent study contact.

4. Provide a financial incentive, with a higher incentive for more distal follow-up assessments.
   The most common reason adolescents reported for staying in the UMASS study over the 1 year f/u period was the financial incentive. For example, offer $5-10 gift card at baseline, double/increase to $10-25 for follow-up surveys.



THANK YOU

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