# Comparison of Parents' Initial Intent and Reported Sharing of their Children's CYP2D6 Research Results at Three Month Follow Up

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## Introduction

- Clinical Pharmacogenetics Implementation Consortium (CPIC) published codeine-*CYP2D6* guidelines in 2012, updated 2014. Both versions recommend avoidance of codeine for CYP2D6 ultrarapid metabolizers and poor metabolizers. Recommendations about alternative opioids are provided.
- *CYP2D6* testing to inform opioid therapy is rare in clinical settings

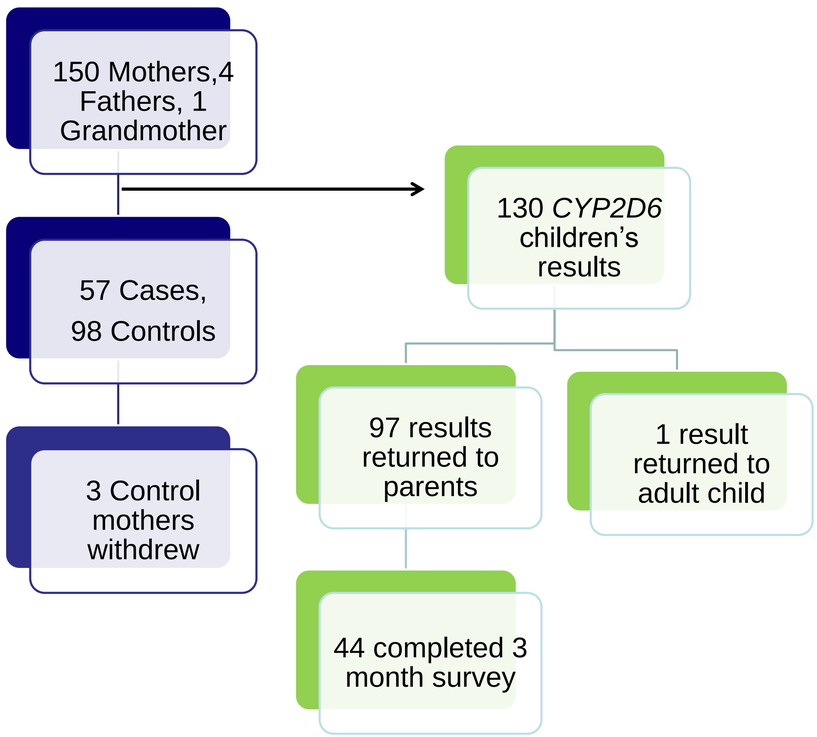
## Aim

Determine parents' intent and actual practice of sharing their child's *CYP2D6* research result as it pertained to codeine.

## Methods

- Potential parent participants were identified through studies in which parents had consented to store their child's DNA for future research at Cincinnati Children's Hospital and agreed to be recontacted.
- TaqMan allelic discrimination system (Applied Biosystem, Forest City, CA) was used to analyze children's stored DNA for 20 *CYP2D6* alleles. When these variants were not identified, **1* was assumed. Long PCR used for *CYP2D6*5* allele (full gene deletion) and *CYP2D6* duplication. Assays performed in CLIA approved laboratory.
- Genetics APRN returned child's CYP2D6 result to parent via telephone
  - Script used for message consistency
  - Individualized script with questions, answers, comments, responses recorded and mailed to parent
- Call transferred to research staff to conduct baseline survey
  - Survey adapted from existing tool[1,2]
  - $10 gift card mailed after completion
- 3 month follow up telephone survey attempted for all participants
  - Requested permission to share result with child's primary provider after completing survey
  - $10 gift card mailed after completion
- All data entered into and managed using REDCap electronic data capture tools hosted at CCHMC.
- Microsoft Excel 2010 used for descriptive statistics

## Baseline Results




Perceived Clinical Utility of *CYP2D6* - Codeine Result at Baseline

| | Strongly agree | Somewhat agree | Somewhat disagree | Strongly disagree |
|---|---|---|---|---|
| Parent can use result for child's care | 72 (74%) | 24 (25%) | 1 (1%) | 0 |
| Doctor can use result for child's care | 78 (80%) | 19 (20%) | 0 | 0 |
| | **Extremely interested** | **Somewhat Interested** | **Not Very Interested** | **Not at all Interested** |
| Interest in having *CYP2D6* test for other children | 52 (53%) | 29 (30%) | 5 (5%) | 1 (1%) |
| | 8 did not have other children, 2 answered "Don't know | | | |

Parent's Baseline Intent to Share *CYP2D6* – Codeine Result

| | Extremely likely | Somewhat likely | Not very likely | Not at all likely |
|---|---|---|---|---|
| Plan to share result with **child's doctor** | 67 (69%) | 28 (29%) | 2 (2%) | 0 |
| Plan to share result **with child** within one year* | 42 | 26 | 8^ | 11^ |
| Plan to share result **with child** before child turns 18 years ^ | 15§ | 2 | 2 | 2 |
| Plan to share result with **pharmacist**** | 26 (27) | 41 (42) | 23 (24) | 6 (6) |

Responses "Don't Know" *2 with child; **1 with pharmacist
^ Child's DOB 1998 – 2013; Median & Mode 2003
§ 2 previously responded "Don't know" to "…within one year"

## 3 Month Results

- 64 parents eligible for 3 month survey
- 44 (69%) parents completed 3 month survey
  - 100% reported they shared child's CYP2D6 result with at least one adult

Adults with Whom Parent Shared Child's CYP2D6 Results at Three Months

| | Shared | Didn't share |
|---|---|---|
| Other parent | 35 (80%) | 9 (20%) |
| Child's PCP | 10 (23%) | 33 (75%) |
| Extended family | 11 (25%) | 33 (75%) |
| Participant's friend | 12 (27%) | 32 (73%) |
| Child's siblings | 11 (25%) | 31 (71%) |
| Others | 3 (7%) | 41 (93%) |
| Pharmacist | 2 (5%) | 42 (95%) |
| Other HCP | 2 (5%) | 42 (96%) |
| Child's school | 0% | 44 (100%) |

Rows that do not equal 44 contain 1 or more "don't know" responses

Comparison of Intention to Share and Actual Sharing at Three Months

| Action | Intention: extremely likely | Reported action at 3 months |
|---|---|---|
| Share with child's doctor | 67 | 8 (12%) |
| Share with pharmacist | 26 | 1 (4%) |

## Summary

- Parents' perceived utility of their child's *CYP2D6* test result for codeine response was high.
- Parents' intent to share the result was high immediately after learning their child's result.
- Although only 23% shared results with their child's primary care provider by 3 months, we anticipate a greater proportion of parents contacted at 12 months will have shared their child's *CYP2D6* result with their child's primary care provider.

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**References:**

[1] Haga SB, et al. Genet Med. 2011;13:723-8. [2] Haga SB, et al. Pharmacogenomics J. 2012;12:197-204. [3]