



Recruitment and Retention Difficulties in a RCT involving Adolescents with Intellectual Disability.


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Rationale



- 2.7% of Australians have ID
- High levels of unmet health needs
- Difficulties with communication and recall
- Losing support from paediatric services



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Education Component

The *Ask* Health Diary and a Curriculum Strategy Guide




ASK
Health Diary

The *Ask* Project

Health Component

The Comprehensive Health Assessment Program (CHAP)



C·H·A·P
COMPREHENSIVE • HEALTH
ASSESSMENT • PROGRAM

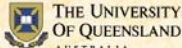
Ask Project

Queensland Centre for Intellectual and Developmental Disability

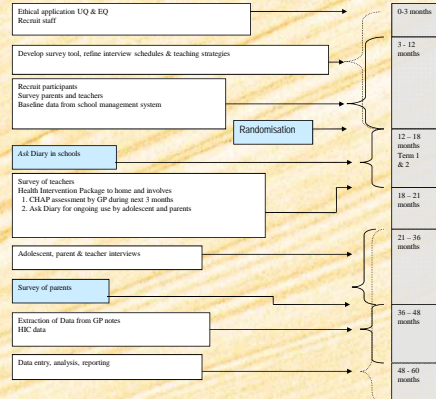
School of Medicine

Aims to determine:

- If adolescents with ID using this package receive better health care and improved health outcomes
- If using this package improves health advocacy by adolescents and their parents
- If this package is acceptable to adolescents, their families, their teachers and their GPs

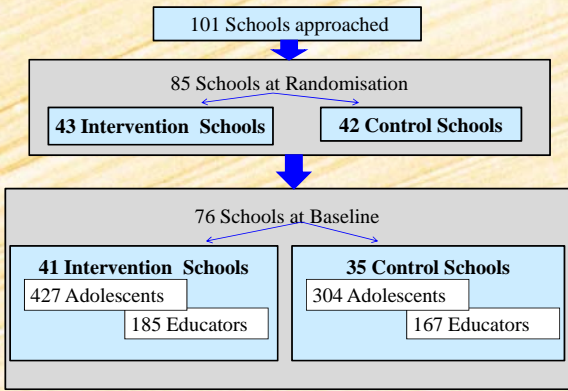


Timeline



Activity	Duration
Ethical application UQ & DQ Recruit staff	0-3 months
Develop survey tool, refine interview schedules & teaching strategies	3-12 months
Recruit participants Survey parents and teachers Baseline data from school management system	3-12 months
Randomisation	3-12 months
Ask Diary in schools	12-18 months Term 1 & 2
Survey of teachers Health Intervention Package to home and involves 1. CHAP assessment by GP during next 3 months 2. Ask Diary for ongoing use by adolescent and parents	18-21 months
Adolescent, parent & teacher interviews	21-36 months
Survey of parents	21-36 months
Extraction of Data from GP notes HBC data	36-48 months
Data entry, analysis, reporting	48-60 months

Recruitment




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    graph TD
      A[101 Schools approached] --> B[85 Schools at Randomisation]
      B --> C[43 Intervention Schools]
      B --> D[42 Control Schools]
      C --> E[76 Schools at Baseline]
      D --> E
      E --> F[41 Intervention Schools  
427 Adolescents  
185 Educators]
      E --> G[35 Control Schools  
304 Adolescents  
167 Educators]
    
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Carer baseline Surveys (n=731)

- 54 Passive Refusals
- 34 Withdrawals
- 21 Left School
- 9 Disconnected
- 12 Unable to Contact
- 4 Claimed Returned
- 1 Deceased


⇒ **596 Participants** (349 Intervention, 247 Control)



GP Recruitment (n= 507)

- 53 Refused
- 3 Passive refusals
- 18 Left practice
- 2 Extended leave
- 5 Patients moved/withdrew


⇒ **426 Consents (84%)**



Intervention Participants (n=349)

- 23 Dr Refused
- 4 No GP
- 1 deceased
- 30 Withdrawals (1 after doing CHAP)
- 26 No CHAP (Will do Exit Survey re diary)
- 27 Lost to Follow-up
- 65 CHAPS not returned

⇒ **173 Current Participants**



Lost to Follow-up

427 Intervention Participants
Recruited

30 Lost before baseline (7.0%)

27 more lost to date (6.3%)



Reasons for not doing CHAP

- Other health issues
- Too busy
- Adolescent won't do it
- Family or adolescent have moved (no new Dr)
- Other family problems



CARER EXIT SURVEY

The Diary

- Do you still have it?
- Have you used it?
- What do you think about it?
- How do you think you could make it better?



The CHAP

- How did the appointment go?
- Were there any problems?
- Did you think it was a good thing to do?



Other Questions

- If you didn't do the CHAP, why not?
- Have you moved house during the course of the project?
- Other questions about the complexity of their lives and the stress involved.

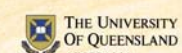


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Thank you

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