



ARISE

African Research And Innovative
Initiative For Sickle Cell Education

Retention Strategies For Life Course Studies of Sickle Cell Disease in Nigeria

A Discussion at the Train-the-Trainer Workshop
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Lead/Speaker : Dr Ramsey M. Yalma,

Lecturer/Consultant Public Health Physician, Department of Community
Medicine, University of Abuja, Nigeria

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Objectives of the Presentation/Discussion

At the end of this discussion we should be able to:

- ◆ Describe the retention strategies for newborn babies in prospective longitudinal studies
- ◆ Decide the retention strategies that may be effective in the proposed ARISE Project Newborn Screening (NBS) and Life Course Study in the Nigerian setting
- ◆ Have some understanding of some contextual issues including the sociodemographic characteristics
- ◆ Successfully carry out a NBS programme in Nigeria based on the available evidence from systematic reviews and meta-analysis



ARISE Project Objectives and the Study Designs

- In addition to the overarching and primary objectives for the EU/ARISE consortium an important secondary objective is:
 - ❖ To evaluate the impact (effect/outcome) of newborn screening and early intervention therapies on the survival of newborn, childhood and adulthood: a life course study of Sickle Cell Disease (SCD)



The Secondary Objectives and the Study Designs

- Given that the life span of the ARISE Project is now less than 4 years, how much time do we consider adequate to evaluate the impact (or rather effect or outcome) of newborn screening and early intervention therapies on the survival of
 - ❖ Newborn ?
 - ❖ Infant?
 - ❖ Childhood?
 - ❖ Adulthood?



Proposed study design for the life course study?

Prospective Cohort Design

- To evaluate the impact (effect or outcome) of newborn screening, one may consider using a prospective cohort study design
- That is if cohorts of newborn babies can be identified who are already exposed to early intervention therapies and another cohort that are not exposed
- Based on the exposure status, the newborn babies are followed up and survival rates and other outcomes of interest are assessed and compared between the exposed and non-exposed cohorts using relative risks/risk ratios etc.



Proposed study design for the life course study?

Intervention/experimental design

- Alternatively, one may consider the use an intervention/experimental study design by conducting new born screening in selected primary/secondary/tertiary health facilities
- Collect sociodemographic and other data and medical history of babies diagnosed with SCD (at baseline)
- Apply the early intervention therapies on the intervention/experimental group while allowing conventional therapies or no therapies as usual on the control group
- Assess survival rates and other outcomes at midline & endline



Proposed study design for the life course study?

- **Qualitative methodology and cross sectional surveys:** These may be useful in meeting the other objectives of the consortium explore contextual issues regarding staff exchange programme, laboratory quality assurance and prevalence of SCD
- What are the ethical considerations and other issues involved in the intervention design, prospective cohort and other study designs?
- Also in using any of the study designs above, an important problem is ATTRITION and non response and the need to retain newborn babies and their parents to complete the study



Retention strategies for prospective cohort and intervention studies

- It is very important to maximize cohort maintenance within high investment research such as the EU/ARISE project
- Retention rates depend on:
 - ❖ Study design characteristics e.g. number of waves, study duration, sample size etc.
 - ❖ Participant characteristics e.g. population type/socio-demographics, gender, age, level of development of a country etc.
 - ❖ The specific retention strategy used
 - ❖ The number/combination of retention strategies



Retention strategies for prospective cohort and intervention studies

Established/Traditional retention strategies:

1. Barrier reduction strategies
2. Follow up reminders
3. Tracing strategies
4. Community building strategies



Retention strategies for prospective cohort and intervention studies

Emerging retention strategies/Modern Innovations/Novel Digital Methods:

- ❖ Social media
- ❖ Electronic reminders
- ❖ Wearable sensors e.g. fit bits
- ❖ Group ware systems e.g. video conferencing etc.
- ❖ Web advertising/Web or mobile surveys



Barrier Retention Strategies

- Assistance with transportation
- Offering the child clinical/other care
- Offering participants alternative methods of data collection e.g. face to face and or over the telephone
- Engaging sub-sample of participants in evaluating data collection methods for the next wave
- Assistance with parking etc.



Follow up reminders

Strategies to improve follow up rates within each wave of assessment or evaluation include:

- Cash/gifts incentives for various levels of assessment completion
- Use of phone calls, short message services (SMS), house visits, e-mail reminders
- Repeat visits
- Repeat questionnaires



Tracing strategies

Collecting detailed participant contact information (Locator documentation):

- Full name
- Traceable address
- Phone number/Alternative phone number
- E-mail address
- Alternative person's contact details & phone numbers
- Using public or non public records to find updated contact information e.g. hospital records, birth registration records etc.



Tracing strategies (con'td)

Sociodemographic/other data of newborn babies:

- Date/time of birth
 - Age
 - Birth weight
 - Genotype/Blood group
 - Apgar score
 - Mode of delivery (SVD, C/S)
 - Place of birth
 - Skilled birth attendance
 - Level of education, occupation, religion/ethnic group or tribe of parents
- (Sending Thank you, Birthday or Holiday Cards)



Community Building Strategies

This involves creating a sense of project community by using

- T-shirts with study logo
- Sharing study results
- News, events with participants via social media, news letters and feedback reports etc.



Which retention strategies may be most effective in Nigeria?

- The strongest strategy based on evidence from systematic reviews and meta-analysis is barrier reduction especially transportation fare/services (1,2,3)
- This is followed by strategies to improve follow up rates including cash and gifts incentives to mothers
- Tracing strategies is also effective where adequate locator documentation is possible e.g. use of the mobile phone (calls/SMS)
- Community building strategies e.g. use of T-shirt and Logo, news and the use of social media (whatsApp and Facebook)
- Overall, a combination of these retention strategies (Digital retention strategies alongside established methods) may be most effective in Nigeria



Conclusion

- What can we learn from other research projects/programmes/literature?
- Consider study design issues e.g. Use very large sample size to minimize attrition, use fewer number of waves for evaluations etc.
- A pilot study may be necessary to test run the entire process



THANK YOU

THANK YOU



References

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