

# Preliminary Recommendations for Effective Outreach and Engagement in the Down Syndrome Community

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## BACKGROUND

A Congressional directive in fiscal year (FY) 2018 appropriations legislation called for a new trans-NIH research initiative on critical health and quality-of-life needs for individuals with Down syndrome (DS). Consequently, the NIH launched a new DS research initiative known as INCLUDE (INvestigation of Co-occurring conditions across the Lifespan to Understand Down syndrome). Source at <https://www.nih.gov/include-project>.

INCLUDE will investigate conditions that affect individuals with DS and without DS, such as Alzheimer's disease (AD), autism, cataracts, celiac disease, congenital heart disease, and diabetes.

## INCLUDE OBJECTIVES

- 1. Conduct targeted, high-risk, high-reward basic science studies on chromosome 21.**
  - Study animal models of DS
  - Explore the effects of multiple genes with a trisomic imbalance for chromosome 21 simultaneously
  - Identify pathways that may be most responsive to new therapies.
- 2. Assemble a study population of individuals with DS.**
  - Add to or expand existing DS cohorts with 'omics data
  - Develop shared databases using common data elements
  - Build on the DS-Connect® registry
  - Develop effective community engagement strategies
- 3. Include individuals with DS in existing and future clinical trials.**
  - Bolster recruitment of people with DS in clinical trials for co-occurring conditions
  - Develop new therapies for DS
  - Leveraging existing clinical trials infrastructure to explore differences in drug metabolism in those with DS and assist in clinical trial design and training for conducting drug trials in people with DS.
  - Expertise from the DSMIG membership will be essential to inform these efforts

See URL: <https://www.nih.gov/include-project/include-project-research-plan>

## COMMUNITY OUTREACH ENGAGEMENT WORKING GROUP

INCLUDE workshop in September 2019 on "Planning a Virtual Cohort for Down syndrome Across the Life Span" led to the creation of a working group focused on Community Engagement.

The group's task order was:

1. Identifying barriers and opportunities for care provider involvement in research.
2. Identifying strategies to aid care providers wishing to serve as conduits for research opportunities for individuals with Down syndrome and their families.
3. Describing potential benefits researchers can provide to the community to improve care and create collaborative relationships.

## BACKGROUND

- Nicole White/Anna Esbensen/Lumind IDSC Foundation survey (Hillerstrom, 2019) on research attitudes in the DS community: 98% in support of research to improve health and independence; 86% desire new drugs, therapies, and interventions; 37% of respondents have concerns about enrolling dependent in research. Barriers to participation: travel; lack of access to results; lack of clarity about purpose of research; invasive procedures.
- The Working Group supplemented this information with interviews with allied health care providers, family members in Spring 2020.

## 4 P's: SOCIAL MARKETING PITCH ACTIVITY

- **Product:** What are the benefits of participation in DS research?
- **Price:** What are the barriers/costs of participating in DS research?
- **Place:** Where do targets (families, self-advocates, providers) spend their time and make their decisions?
- **Promotion:** What persuasive communications can we use to convey the benefits of DS research participation?

## DEFINING THE STAKEHOLDERS

- Individuals with Down syndrome
- Family members or caregivers
- Healthcare providers (health professional, therapist, teacher, clinician, researcher, clinician researcher, etc.)

## 4 P's: OUTREACH STRATEGIES FOR EACH STAKEHOLDER

Working group discussions led to initial social marketing strategies for each stakeholder group:

### Individuals with Down syndrome

- **Product:** new information that can improve your life and the life of others with DS
- **Price:** anxiety about what the research will involve; time, transportation
- **Place:** family members, advocacy groups, educators, trusted allied health providers
- **Promotion:** This can benefit you in the short term (payment) and long term (learning important new things about DS)

### Family member or caregiver

- **Product:** benefits to research findings, helping others, return of results and resources to families
- **Price:** location, convenience, risk
- **Place:** must be in a convenient location to family, a way for young siblings to be occupied during research
- **Promotion:** increase trust, convenience, low risk, civility and respect, sharing success stories of gains realized from research
- We want to close the gap between interest in research and participation in research
- We need more studies that are observational in nature first to improve overall health and quality of life in DS.
- **Healthcare provider (health professional, therapist, teacher, clinician, researcher, clinician researcher etc.**
  - **Product:** New insights about DS to inform practice; More effective intervention and treatment to support their patients
  - **Price:** High effort, minimum payoff; Long timeline from recruitment to findings
  - **Place:** Place—DS association websites; Research weekends with DS organizations; Email lists; Flyers; Social media
  - **Promotion:** We're all in this together; Advanced/transformatory methodologies; Serve as a bridge to more advanced treatments

## DS-CONNECT REGISTRY PARTICIPATION

### Goals for DS-Connect®: The Down Syndrome Registry

- Increase the number of participants
- Encourage under-represented minorities for participation
- Use DS-Connect to support cohorts and clinical trials

NIH National Institutes of Health  
DS-Connect® is a powerful resource where people with Down syndrome and their families can:

- Connect with researchers and health care providers
- Express interest in participating in certain clinical studies on Down Syndrome, including studies of new medications and other treatments
- Take confidential health-related surveys. These surveys are aimed at better understanding of the health of people with Down Syndrome across their lifespans.

Join the Registry Set up a Professional Account Información en español

## NEXT STEPS

- Create various outreach and promotional strategies and materials using the 4 P's concept
- Engage the community early on and continuously
- Return of results is very important
- DS-Connect is a powerful online family registry that connects all stakeholders including Individuals with DS, their families or caregivers, and healthcare providers to research opportunities

<https://www.nih.gov/include-project>