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Evaluating the Feasibility of a Personalized Endpoint in Down Syndrome-associated Alzheimer's Disease: Inventory-facilitated Goal Attainment Scaling



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Introduction



The Value of Goal Attainment Scaling (GAS) in Down syndrome-associated Alzheimer's disease (DS-AD)

The LIFE-DSR GAS DS-AD Sub-study

A 16-month long prospective study that aims to:

- Assess the feasibility and acceptability of implementing inventory-facilitated GAS in the DS-AD population
- Assess the content validity of the DS-AD Goal Inventory

What are the challenges in evaluating health outcomes in individuals with DS-AD?

1

Disease Heterogeneity

Evaluating health outcomes in individuals with Down syndrome (DS) can be difficult due to varying levels of baseline function and cognition. This complexity is further exacerbated by the onset of dementia.

2

Individual Response to Treatment

There is also growing evidence that individuals with DS and dementia respond differently to treatment when compared to dementia patients without DS.¹

How GAS addresses these challenges:

1

GAS is Responsive

GAS is sensitive to change; it captures incremental but meaningful change in multiple domains.

2

GAS is Individualized

GAS is a personalized clinical outcome assessment that captures lived experience from the patient's and/or caregiver's perspective.

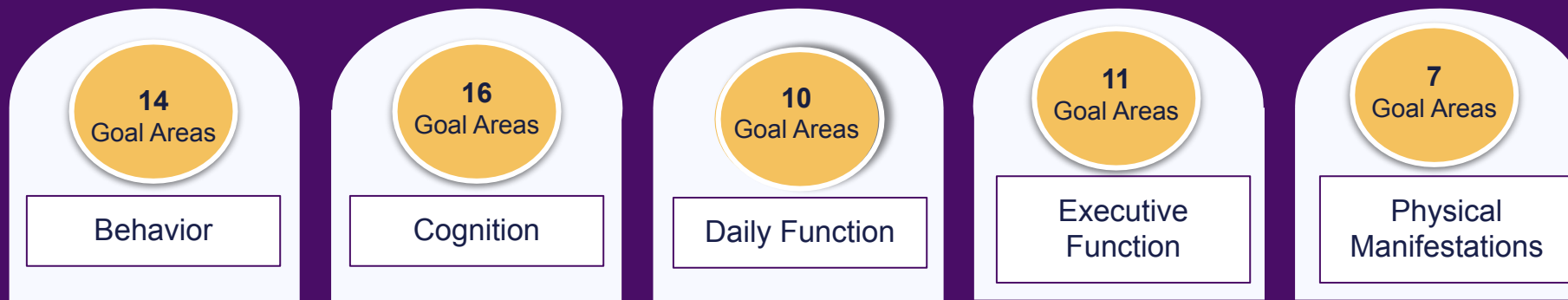
Goal Inventories Streamline the Process of Selecting Goals For a Personalized Endpoint

What are Goal Inventories?

Goal Inventories or menus are lists of goals, symptoms and challenges that are identified by patients and clinicians. They need to be uniquely developed for each study protocol to ensure alignment with treatment targets.

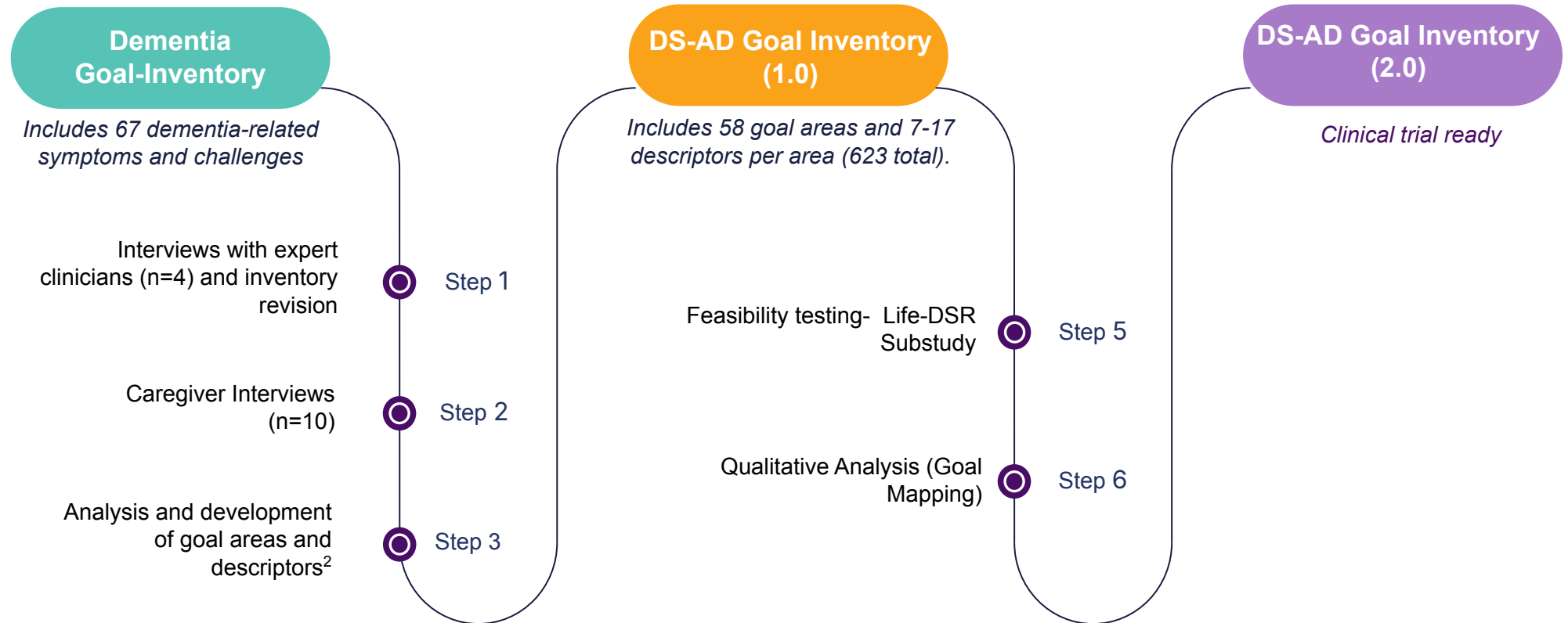
DS-AD Goal Inventory 1.0

Based on expert clinician and caregiver input, the DS-AD goal inventory was developed consisting of 58 goal areas, each with 7-17 descriptors (623 total) divided over five domains.

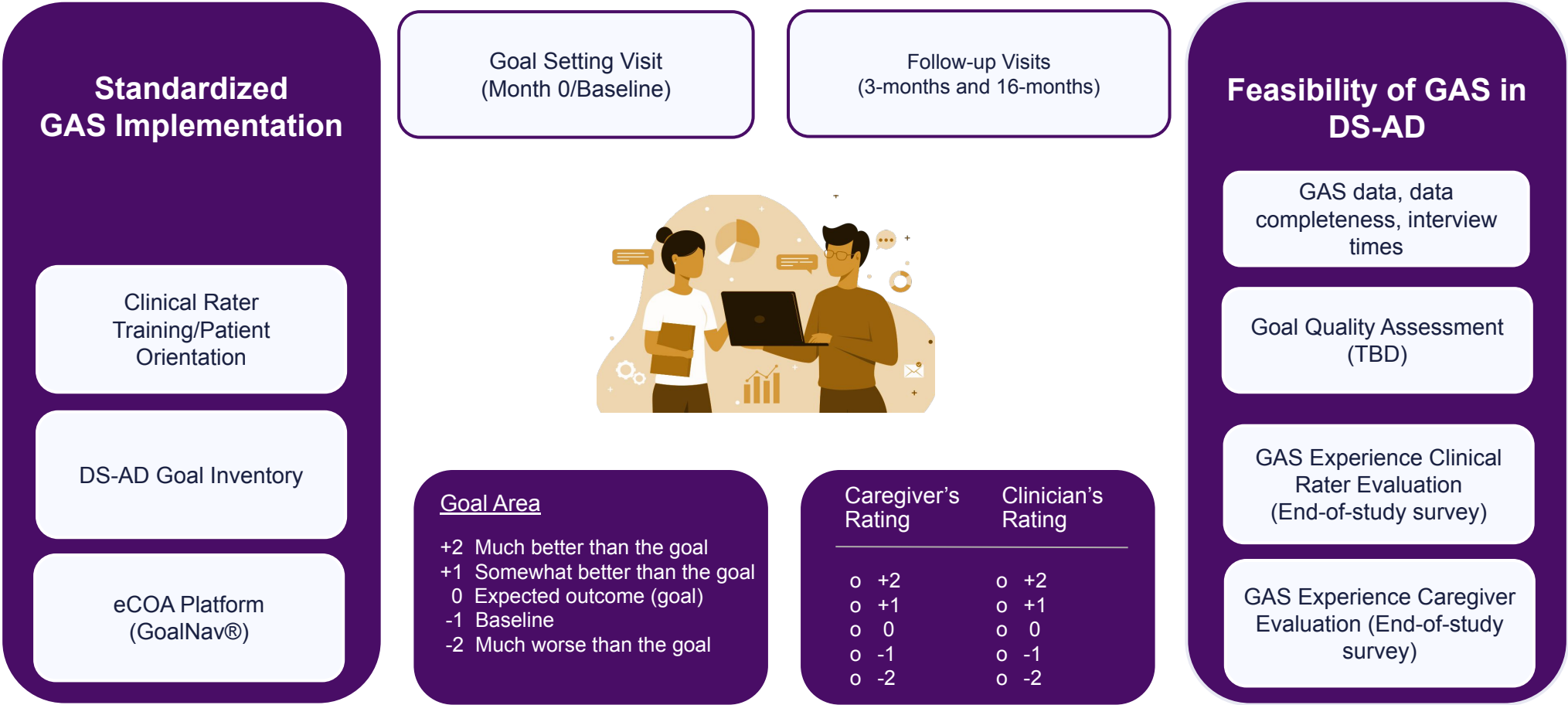


Methods

DS-AD Goal Inventory Development Methodology Overview

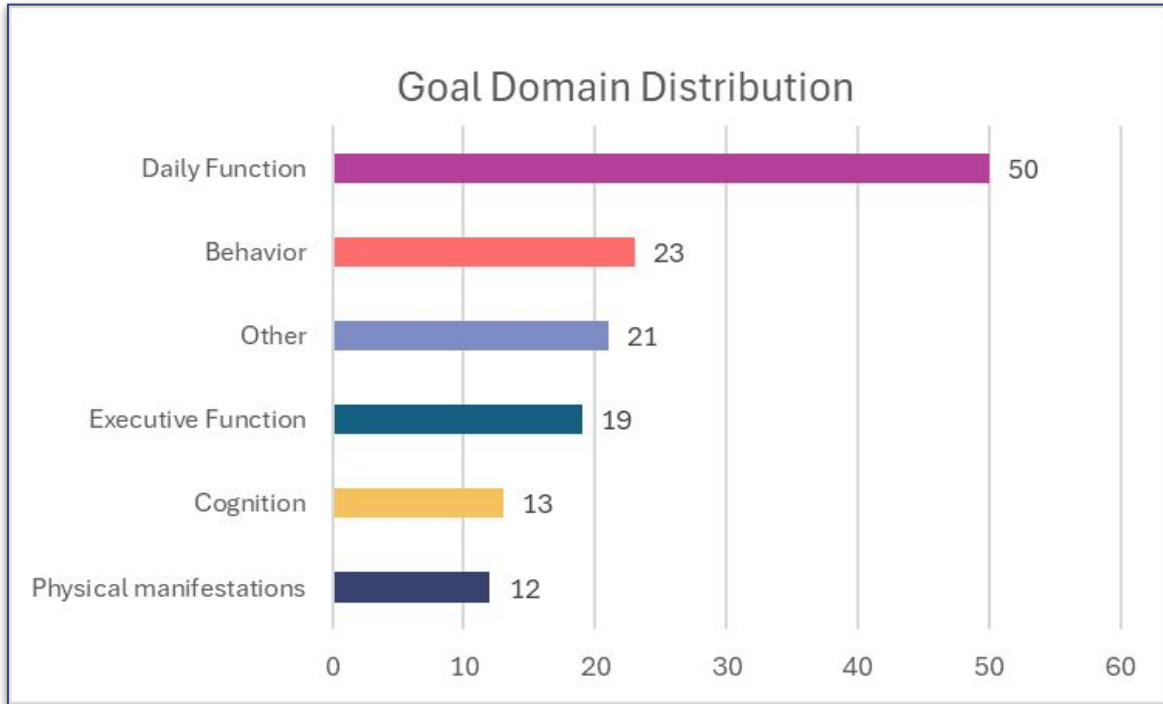


LifeDSR GAS SubStudy to Assess Feasibility of GAS in DS-AD



Results

Goal Domain Distribution

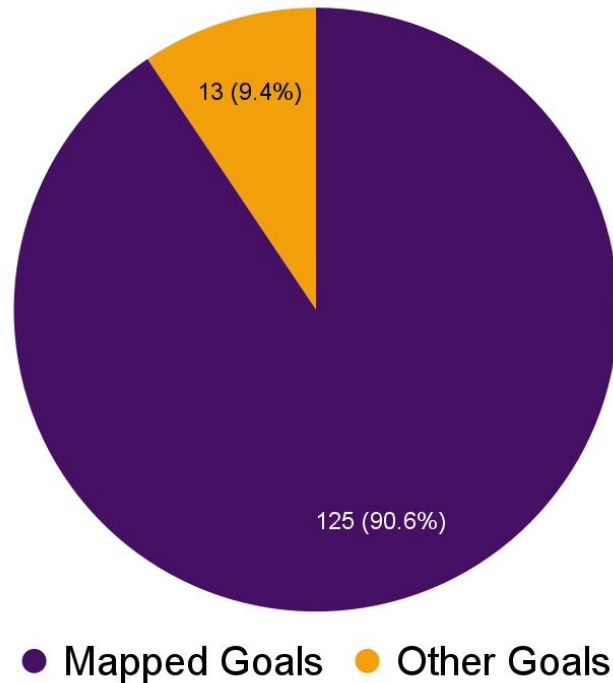


Goal Domain Distribution (before qualitative analysis of goals)



- At baseline, 46 caregivers set a total of 138 goals.
- 117/138 (85%) goals were chosen from the goal inventory. 21/138 (15%) were 'other' goals, meaning they were not chosen from the goal inventory.
- 17/46 participants set at least one 'other' goal.
- Most goals were chosen from the goal inventory.

Content Validity: Goal Mapping Results



Goals chosen from the inventory

Of the 117 goals selected from the inventory, 6 goals could not be mapped to any existing goal areas on the DS-AD inventory.

'Other' goals

Of the 21 'other' goals, 14 were mapped back to existing goal areas in the inventory. 7 goals did not match any items on the inventory.

DS-AD Inventory (91%)

91% (125/138) of the goals could be mapped back to the DS-AD inventory.

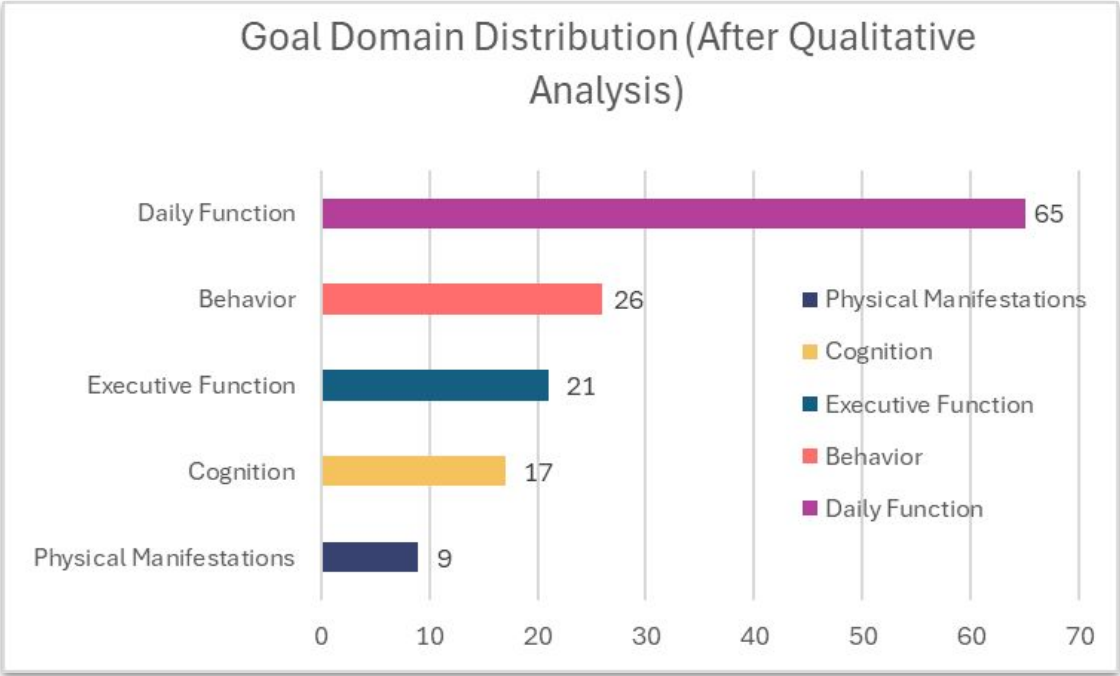
9%(13/138) goals could not be mapped back to any items in the inventory.

New Goal Areas Proposed:

Two new goal areas and 13 descriptors are proposed to incorporate the 13 goals that do not align with items in the inventory:

- Physical Activity and Exercise
- Nutrition, Dietary Habits

Content Validity: Goal Domain Distribution Post Qualitative Review



Goal Domain Distribution (post qualitative analysis of goals)



Feasibility: GAS Data

1



Participation and Attrition

Participants (n) completed each visit:

- Goal-Setting Interview (Month 0): 46
- Follow-up Interview (Month 3): 45
- Follow-up Interview (Month 16): 43

Total Attrition: 6.61%

2



Data Completeness

All caregivers set the recommended 3 goals. Generally, GAS is considered more feasible in a population if they can set at least 3 goals.

All goal attainment levels were completed for all goal scales.

At the 3-month follow-up, clinician and caregiver ratings were provided for all but two goals (unrated for one participant).

At the 16-month follow-up, ratings were provided for all goals of the 43 participants who completed the visit.

3



Interview Duration

Baseline/goal-setting interview

Mean interview time: 38.57 minutes (SD = 10.41, Range: 13-60 minutes).

3-Month Follow-Up

Clinical raters recorded interview times for 44/45 participants.
Mean interview time: 17.98 minutes (SD = 9.54, Range: 5-35 minutes).

16-month follow-up

Mean interview time: 14.49 minutes (SD = 4.74, Range: 5-25 minutes).

4



Goal quality - SMART criteria

n (%)

Specific 53 (38.4%)

Measurable 104 (75.4%)

Achievable 127 (92.0%)

Relevant 134 (97.1)

Time-Bound 138 (100%)

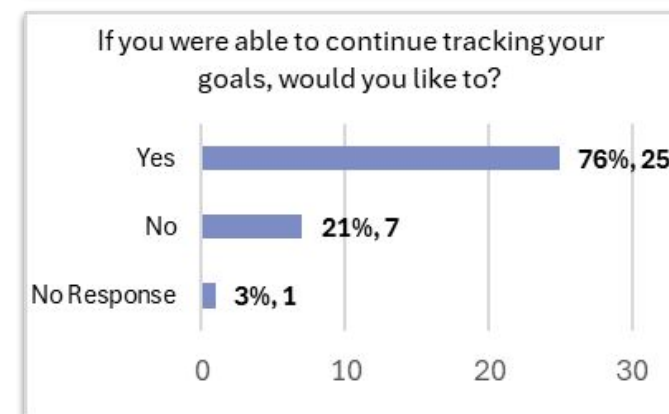
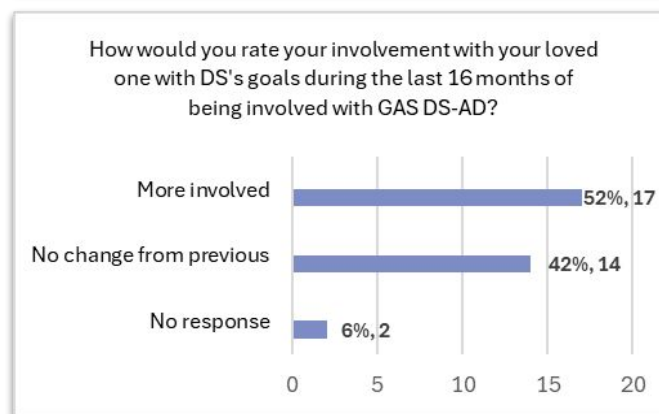
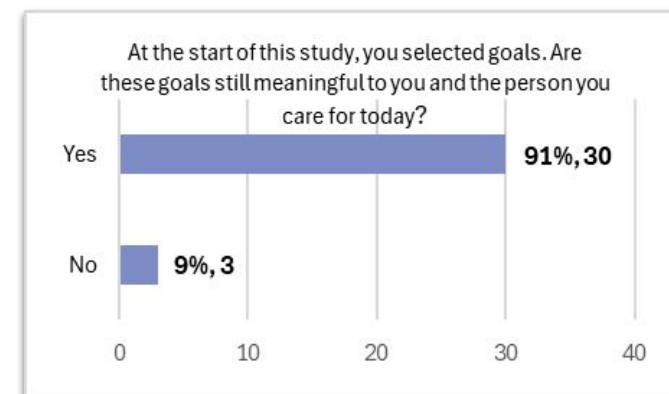
Feasibility: Caregiver Perspective

Caregiver End-of-Study Survey

33 caregivers completed the survey.

Mixed-methods survey with 11 questions: 5 multiple choice and 6 open-ended.

Multiple choice questions were summarized by frequency and percentage. Open-ended questions were analyzed thematically.



Feasibility: Caregiver Perspective



Enhanced Communication and Shared Understandings

Most (n=30) caregivers agreed that the GAS process increased communication with the clinician.

Interactions were more frequent and productive.

Caregivers felt they could more effectively express their loved ones' goals, symptoms, and challenges, leading to a shared understanding with clinicians. As a result, they felt validated in their experiences and supported.



Goals are Practical and Relevant to Daily Life

Twelve caregivers noted that the goals set at baseline remained meaningful, as they were practical and focused on essential life skills and long-term objectives like improving independence and communication.



Informative and Eye Opening

Insights into the participant's progress and status

Caregivers felt that their involvement with the process provided clearer insights into the participant's progress and status, and areas unlikely to change.

New Perspectives and Knowledge

Eight described their experiences as informative or eye-opening, gaining new insights into their loved one's symptoms and challenges, as well as the range of available options



A Sense of Meaningful Achievement and Satisfaction

Seven caregivers described their experiences as meaningful and rewarding, expressing satisfaction in observing participants' progress.



Key Findings and Takeaways

1. Early findings suggest that GAS is feasible in the DS population.
2. The DS-AD Inventory and Content Validity
 - a. Most (85%) goals were chosen from the DS-AD inventory, and 91% (125/138) of the goals could be mapped to items in the inventory, suggesting the inventory comprehensively covers important challenges and symptoms for this population.
 - b. To incorporate the 13 goals around improving diet and physical activity, two new goal areas and 13 descriptors have been suggested.
3. Caregivers largely reported positive experiences.
4. Caregivers highlighted enhanced communication with clinicians and shared understandings, new perspectives and knowledge gained, a sense of achievement and satisfaction, and the ability to set relevant and practical goals focused on essential life skills.

Discussion

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1. Ballard C, Mobley W, Hardy J, Williams G, Corbett A. Dementia in Down's syndrome. Lancet Neurol. 2016;15(6):622-636. doi:10.1016/S1474-4422(16)00063-6
2. Knox, K., Stanley, J., Hendrix, J.A. et al. Development of a symptom menu to facilitate Goal Attainment Scaling in adults with Down syndrome-associated Alzheimer's disease: a qualitative study to identify meaningful symptoms. J Patient Rep Outcomes 5, 5 (2021). <https://doi.org/10.1186/s41687-020-00278-7>

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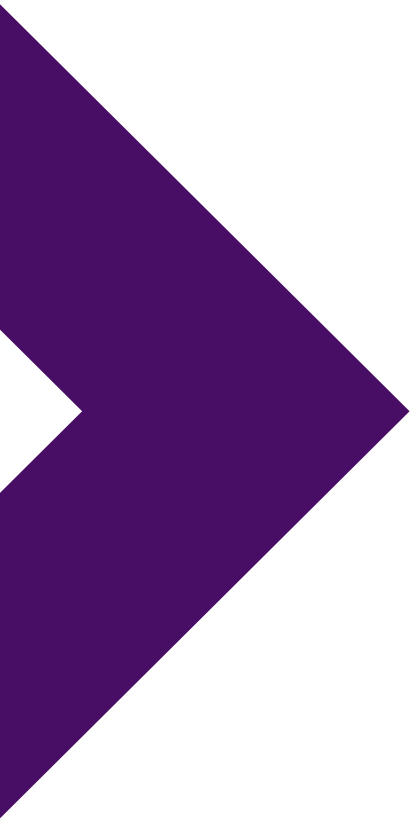
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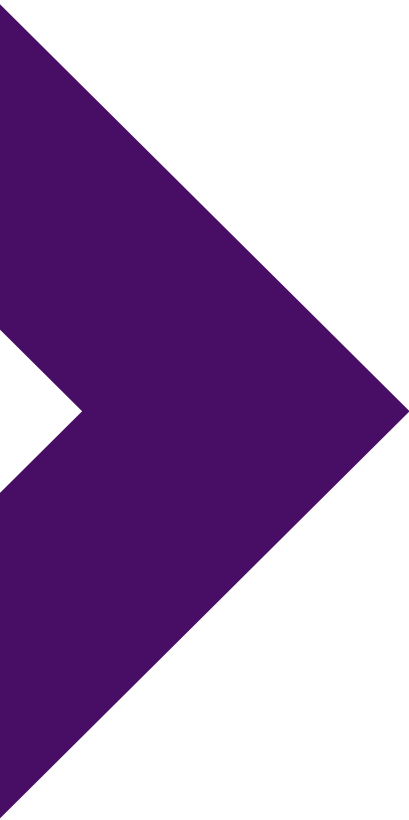


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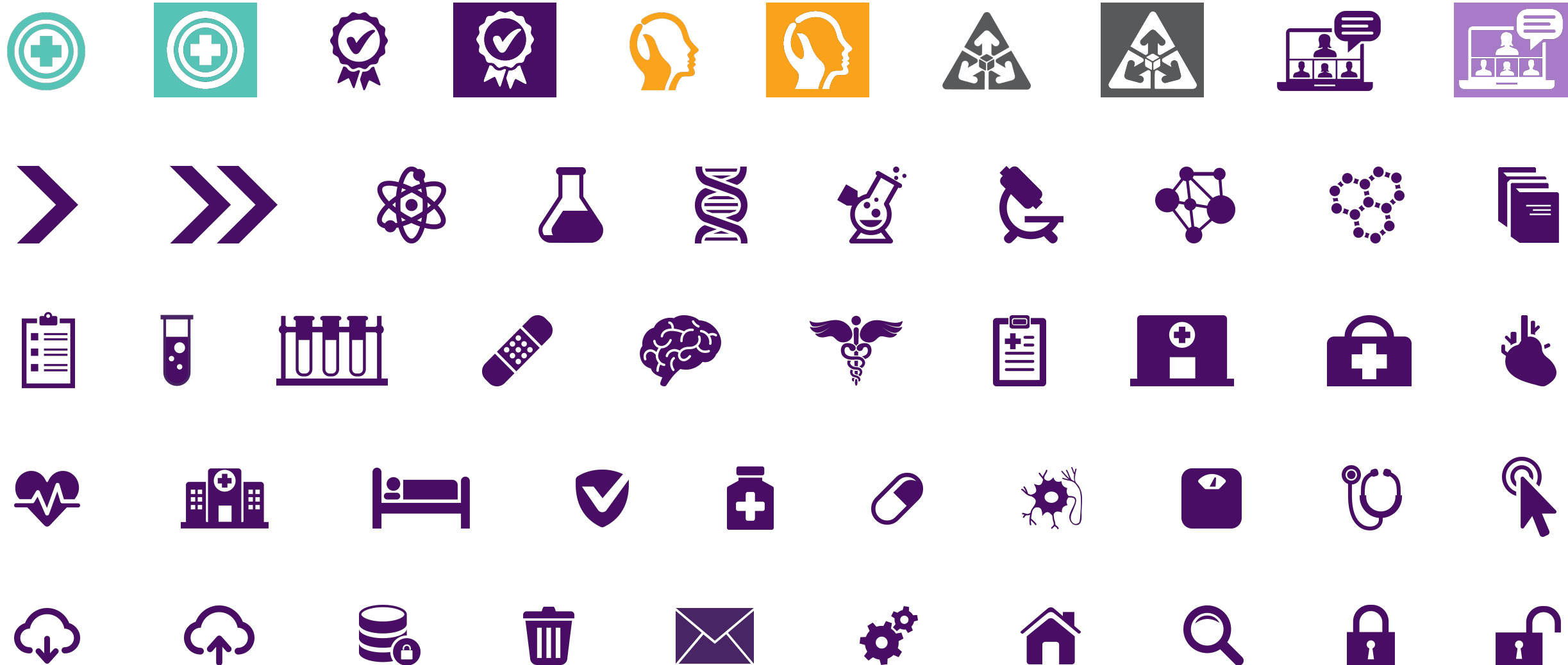
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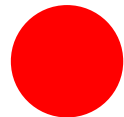
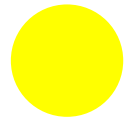

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DS-AD Goal Inventory Development Methodology Overview

