

## Scoping Review Protocol Draft

Modified on 3/07/2023

Team members:

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1. Title: Characterization of communication and feeding development within DYRK1A
2. Structured Summary: We seek to develop a comprehensive report of communication and feeding skills for children/persons with DYRK1A which has been documented across studies. We will search multiple databases and include articles/evidence based on human participants.
3. Rationale: Children with DYRK1A syndrome commonly experience communication and feeding delays, some children have notably severe deficits. However, empirical evidence of the expected ranges in these skills and description of prognosis/progress are limited. Thus, speech-language pathologists are lacking guidance for conducting evaluations and setting goals to promote communication and feeding abilities for these unique children.
  - What tools have been used?
    - o What behaviors seen/described?
    - o How deviant from normal?
4. What tools have been used to describe communication and feeding skills in persons with DYRK1A? Secondarily, what behaviors have been described in the literature and how deviant from normal were the observations?
5. Secondary part: How deviant is performance from normal or expected milestones?
6. Initial draft of protocol was conducted by Dr. Pitts, Grace Brennecke, and Hailey Hirsch and submitted for review to Q. Eileen Wafford. Protocol was guided to fulfill Preferred Reporting Items for Systematic Review and Meta-analysis Protocols (PRISMA-ScR). Protocol will be registered through Northwestern University.
7. Inclusion and Exclusion Criteria:

### Inclusion Criteria

1. Publication of January 2000 through January 2023. Rationale: More recently identified syndrome, recognized in 2015.

2. Publication written in English.
3. Publication comes from a peer review journal, is a publication of abstract/conference proceedings/poster, or is a thesis/dissertation.
4. The design of the study was single-subject, case report, cross-sectional, time series, prospective cohort and randomized control studies that provide data on DYRK1A in human subjects in regard to communication (cognition included) and feeding skills.
5. Assessment and reporting of quantitative (raw values or group statistics) or qualitative (individual descriptive assessment regarding professional observations, parent report, or child interview) for children with DYRK1A.

#### Exclusion Criteria

1. Publication published before January of 2000
2. The publication is written in any language other than English that cannot be translated through university free services.
3. The design of the study did not include human participants.
4. Does not report individual/group data that is qualitative or quantitative regarding communication or feeding.
5. Data reported in the study does not include DYRK1A participants.
6. The data is a duplicate.

#### Information Sources:

PubMed MEDLINE (NIH/NLM)  
CINAHL Plus with Full Text (Ebsco)  
Cochrane Library (Wiley)  
Embase (Elsevier)  
Linguistics and Language Behavior Abstracts (ProQuest)

#### 8. Search/Terms and Strategies:

We will work with a research librarian (QEW) to develop a comprehensive search strategy with Medical Subject Headings (MeSH) and keywords that describe DYRK1A, communication, and feeding. We will develop the search in PubMed and adapt it to CINAHL Plus with Full Text (Ebsco), The Cochrane Library (Wiley), Embase (Elsevier), and Linguistics and Language Behavior Abstracts (ProQuest). Searches will be limited to studies published in English and between 2000 and the present. No restrictions will be imposed on geography or publication type.

PubMed Search String:

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((("Protein Serine-Threonine Kinases"[Mesh] AND (Dual-specificity[tiab] OR "1A"[tiab])) OR ("Protein-Tyrosine Kinases"[Mesh] AND (Dual-specificity[tiab] OR "1A"[tiab])) OR ("DYRKs 1A"[tiab] OR "DYRK 1A"[tiab] OR DYRK1A[tiab] OR DYRKs1A[tiab] OR "Dual specificity tyrosine phosphorylation regulated kinase 1A"[tiab] OR "Dual specificity tyrosine regulated kinase 1A"[tiab])) AND (((("Communication"[Mesh]) OR ("Speech Disorders"[Mesh]) OR (articulat*[tiab] OR communicat*[tiab] OR dysarthria*[tiab] OR dysglossia*[tiab] OR "interpersonal interact*" [tiab] OR language*[tiab] OR misarticulate*[tiab] OR nonverbal*[tiab] OR "social interact*" [tiab] OR "social skill*" [tiab] OR sound*[tiab] OR speak*[tiab] OR speech[tiab] OR spoken[tiab] OR syntax*[tiab] OR verbal*[tiab] OR vocal*[tiab] OR word[tiab] OR words[tiab]) OR ("alternative augmentative"[tiab] AND AAC[tiab]) OR (((phonolog*[tiab] OR disarticulation[tiab]) AND (impair*[tiab] OR dysfunction*[tiab] OR disorder*[tiab]))) OR ("Feeding Methods"[Mesh]) OR ("Deglutition Disorders"[Mesh]) OR ("Deglutition"[Mesh]) OR (chew*[tiab] OR deglutit*[tiab] OR diet*[tiab] OR dysphagia*[tiab] OR eat[tiab] OR eats[tiab] OR eating[tiab] OR enteral*[tiab] OR feed*[tiab] OR food*[tiab] OR gastrostom*[tiab] OR ingest*[tiab] OR masticat*[tiab] OR nutrition*[tiab] OR swallow*[tiab] OR syntax*[tiab] OR verbal*[tiab] OR vocal*[tiab] OR word[tiab] OR words[tiab]))) AND (2000:2023[pdat])) AND English[Language]
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9. Selection of Sources of Evidence: Team librarian and author (QEW) will complete deduplication. Two authors (HH and GB) will independently screen titles and abstracts of search results for inclusion/exclusion criteria with reliability established for 20% of the search results. Three authors (HH, GB, and LP) will review inconsistencies present those to the Team (HH, GB, LP,) to determine updates to protocol by discussion and consensus. Disagreement will be resolved through discussion and consensus across three authors (HH, GB, and LP). Two authors (HH and GB) will independently review full-text items for data abstraction based on inclusion and exclusion criteria. References of items passing the initial screen will be also hand-reviewed for consideration for inclusion. All screening and full selection processes will be documented in an excel database and/or Rayyan software.
10. Data charting process: LP will create a structured data extraction form in Microsoft Excel. This will be independently trialed by HH and GB on 20% of the full-text included artifacts. Three authors (HH, GB, and LP) will review inconsistencies present those to the Team (HH, GB, LP) to determine updates to protocol by discussion and consensus. Data extraction will include article title, authors, institution, year of publication, sample size, participant diagnoses, age, qualitative reports of communication and feeding, and quantitative raw scores for individual and group assessments. Reliability will be assessed between and within raters.
11. Data Items: Data extraction will include article title, authors, institution, year of publication, sample size, evaluation tools, participant diagnoses, age, qualitative reports of communication and feeding, and quantitative raw scores for individual and group assessments.
12. Study quality and bias will be evaluated for the included articles. Review of all artifacts meeting inclusion criteria will be conducted by two authors (HH & GB) using the NIH Quality Assessment Tool for Observational Cohort and Cross-Sectional Studies and the

Strengthening the Reporting of Observational Studies in Epidemiology (STROBE) checklists.

13. Included items will be categorized into two subsections as addressing either communication or swallowing. Thematic analysis of each subsection will be conducted by two authors (HH and GB), disagreement will be handled by a third author (LP). Quantitative data that can be combined be analyzed via RevMan5 (The Cochrane Collaboration Review).