A background image showing the faces of several smiling children, with a green semi-transparent rectangle overlaid in the center containing text.

# **Developing a working paper to cultivate ethically sustainable relationships among stakeholders when nonprofits fund pediatric cancer trials**

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on behalf of the Coalition Against Childhood Cancer (CAC2) Ethics Think Tank



**VIRTUAL CONGRESS**  
OCTOBER 21-24, 2021

# Our Values

...always put the children and their families first in everything we do.



## Respect

Enable the community while respecting our members' unique missions



## Efficiency

Strive for cost effectiveness and efficiency with resources



## Inclusiveness

Emphasize inclusiveness and collaboration towards our common goals



## Amplify

Help give voice to the community and amplify it in a coordinated fashion



## Drive


Stay action-oriented and flexible



**CAC2**  
COALITION AGAINST  
CHILDHOOD CANCER











**CAC2 fosters and sustains greater levels of collaboration, information exchange, and learning across the childhood cancer community through agreed upon initiatives in the areas of advocacy & awareness building, family support, and research & treatment.**



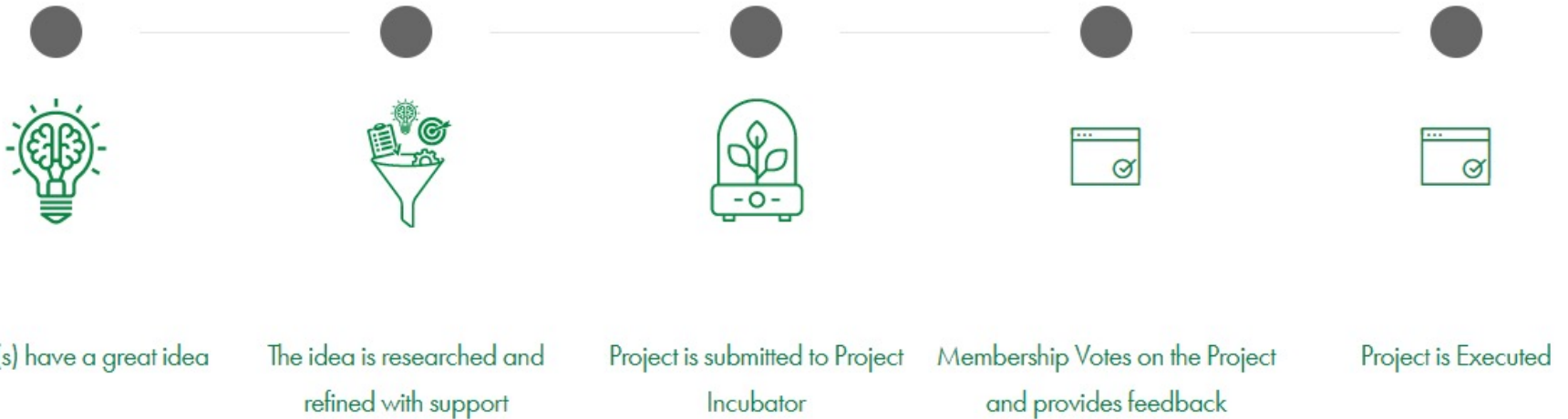
# Project Genesis

-  June 2017 Annual Summit –A 'seed idea' is planted
-  June 2018 Annual Summit– The 'seed' takes root
-  August 2018 – Preliminary review reveals paucity of data
-  November 2018 – Project Incubator Initiated

# CAC2 Project Incubator Process



CAC2 Project Incubator:  
Where Collaborative Innovation grows



# CAC2 Ethics Think Tank Project Aim



To develop a working paper identifying both the potential ethical issues charities face when funding research as well as the suggested best management practices (BMPs) charities may use in dealing with those issues

# CAC2 Ethics Think Tank Project Aim



What are the ethical obligations and relationships of charitable organizations to the following stakeholder groups when funding pediatric clinical trials

- Patients and families
- Donors
- Researchers
- Sponsors

# Systematic Review Methods

- Participatory Consensus Approach
- Reviews included:
  - Peer reviewed journal articles
  - Commentaries
  - Published newsletters
  - Concept papers
  - White papers indexed in PubMed and Web of Science
- Article must be published in English:
- Discussed ethical, legal, social and/or public policy considerations of partnerships between non profit patient advocacy organization and:
  - Researcher
  - Sponsor
  - Donor
- Proposed research funding for a clinical trial (regardless of design)



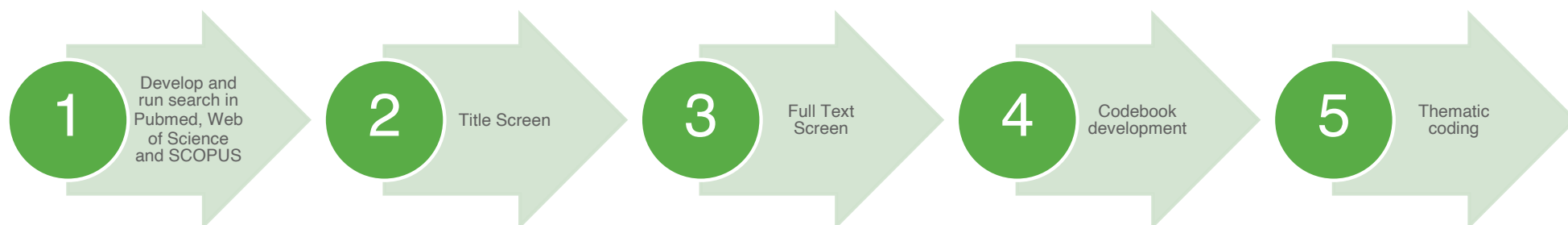
## Literature Review Exclusion Criteria

- Discussion of strategies and practices related exclusively to corporate social responsibility
- Financial conflicts of interest without addressing underlying ethical, legal or social considerations for nonprofit organizations

# Literature Review Methods powered by

Covidence multi- reviewer software

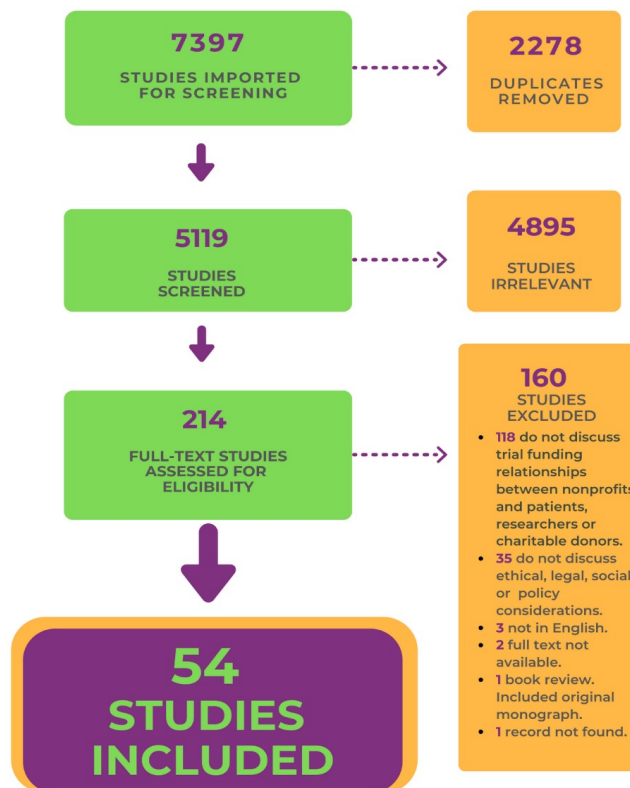
8 member team engaged in Steps 1-4



3 member team engaged in Step 5

# PRISMA reporting diagram

## LITERATURE AUDIT



# Overview of Results

- Nonprofit organizations are a growing source of trial funding, but are not subject to the same oversight as industry, academia etc.
- Trust and transparency are critical when nonprofits are considering funding a trial and throughout its lifecycle and are best maintained when nonprofits select trials that:
  - undergo rigorous scientific and ethical evaluation
  - disclose conflicts of interests, real or perceived among all actors
  - regularly report trial progress, milestones, and results
  - develop an agreed-upon framework for openly sharing trial results
  - keep donors informed about the impact their support is having

# Remaining Knowledge Gaps

- Managing relationships when individuals fit into more than one stakeholder group i.e. donor and patient; researcher and sponsor
- Is direct recruitment of patients involved with the nonprofit funder ethically acceptable?
- Ethical issues surrounding nonprofits with a financial interest in the commercialization of a specific drug, sometimes otherwise called venture or entrepreneurial philanthropy



## Future Directions

- Develop an evaluation framework to track progress on white paper recommendations
- Conduct internal survey of CAC2 members to determine applicability and remaining gaps

## Ethics Think Tank Members

- Caitlyn Barrett, CureSearch
- Vickie Buenger, Individual Member
- Cindy Campbell, Ty Louis Campbell Foundation
- Robin French, The Morgan Adams Foundation
- Donna Ludwinski, Solving Kids' Cancer (Co-Lead)
- Vasiliki Rahimzadeh, Postdoctoral Fellow, Stanford Center for Biomedical Ethics
- Amy Weinstein, Pediatric Brain Tumor Foundation (Co-Lead)
- Susan Wolfert, Taylor Mathews Foundation



# Thank you!

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