

# Understanding the use of the “Family Veto” to withdraw consent to organ donation: A scoping review

## INTRODUCTION

- 90% of Canadians support the concept of organ donation
  - Only one-third of Canadian adults are registered as donors<sup>1</sup>
  - Disparity is heightened by the “family veto”
  - 15-20% of families in Ontario ultimately decline organ donation when a decision to donate has **already been made** by the deceased<sup>2</sup>
  - Over **4,300** Canadians are presently waiting for a transplant<sup>3</sup>
- Family veto (FV) occurs when the family of a deceased person – who had explicitly expressed their desire to donate prior to their death – withdraws consent to donate**
- The legality and ethics of the FV are intensely debated

## OBJECTIVES

What are the main themes and conclusions in the literature on families vetoing or overruling previously given consent to organ donation?

- Objective:** Produce a scoping review of diverse literature, including legal / ethical commentary, qualitative and quantitative empirical research, and systematic reviews in order to capture:
  - (1) Underlying reasons why families may choose to veto consent to donate;
  - (2) Why healthcare providers or hospitals may choose to allow vetoes to take precedence over donor consent
  - (3) Public attitudes towards FV; and
  - (4) Proposed responses to the use of FV
- Future work:** Evaluation of the legality of the FV under Canadian law

## METHOD

This scoping review is guided by the Preferred Reporting Items for Systematic Reviews and Meta-Analysis protocol for scoping reviews (PRISMA-ScR). We conducted a search of legal and scientific/medical research databases using a common search string adapted on an as-needed basis to fit the requirements of the following databases: MEDLINE, Embase, CINAHL, LexisNexis, the Index to Legal Periodicals, and the Law Journal Library (HeinOnline). The search string included terms (and their variants) relating to the following concepts: (1) Organ donation AND (2) Consent AND (3) Family decision-making. Results were collected in July 2022.

Where abstracts were unavailable and the suitability of a source was unclear from title alone, a full-text search was conducted based on the following terms: family, override, overrule, veto, wish, intent-, decision, and/or desire. This screening process resulted in a final set of 90 articles, all of which were used in this review.

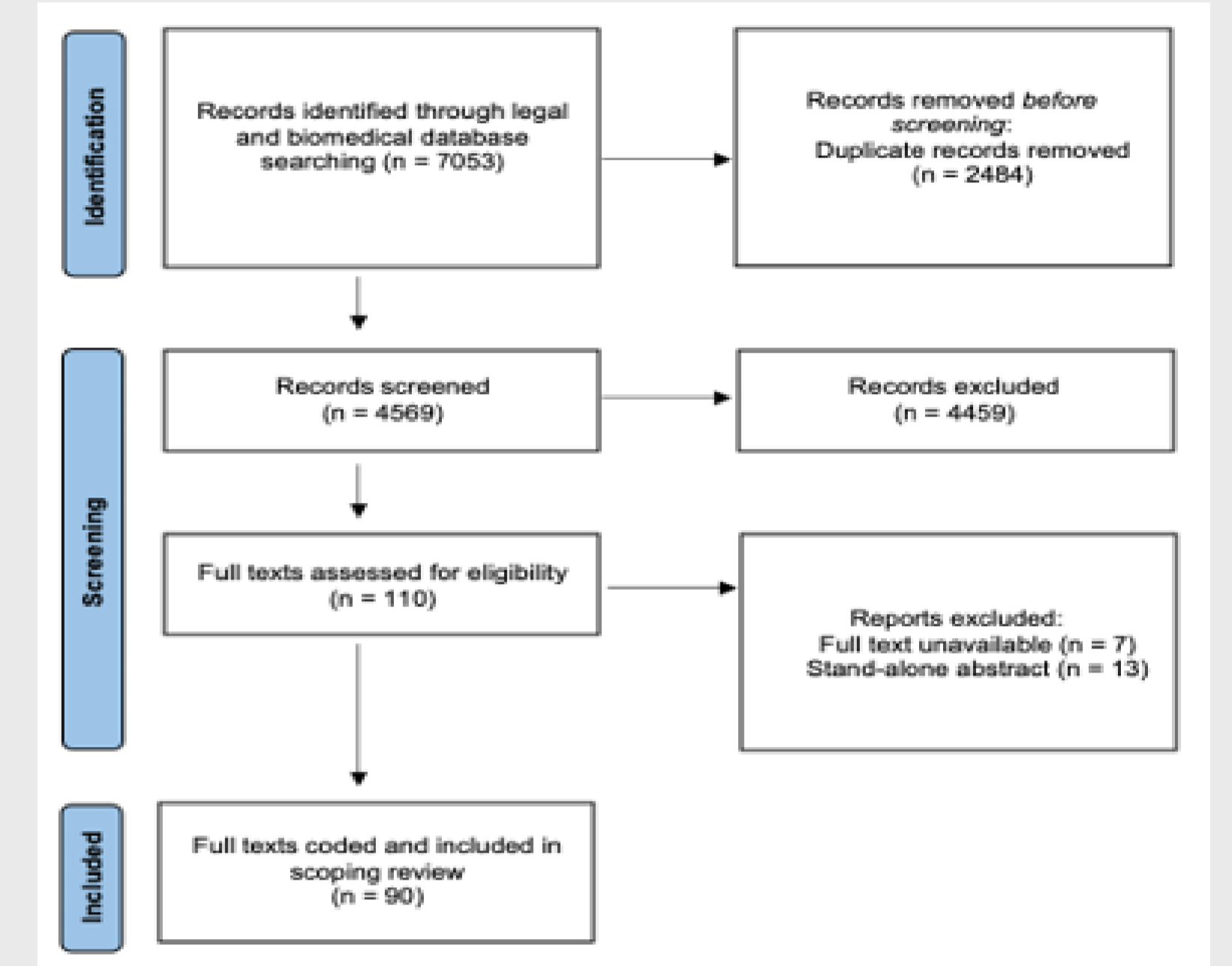


Figure 1: Flowchart of the screening process

## RESULTS

Nine main themes were identified: (1) definitions and context surrounding the family veto; (2) rates of the family veto; (3) tensions between the family veto in law versus in practice; (4) physician duties, and whether they are owed to the deceased, the family, the recipient, or the ODT system more generally; (5) reasons why the family veto is pursued or allowed; (6) reasons why the family veto should not be allowed; (7) proposed solutions to the family veto; (8) the relationship between the family veto and opt-in versus opt-out donation systems; and (9) the legislative / legal framework surrounding family override (and the acceptance or prohibition thereof).

| Theme                     | # Articles | Main Point(s) Reflected in the Articles  |
|---------------------------|------------|--|
| (1) Definition & Context  | 43         | <ul style="list-style-type: none"> <li>“Family veto” refers to posthumous overruling by the family of deceased person’s previously given consent to donate</li> <li>FV is recognized as controversial and as posing practical challenges for HCPs</li> </ul>   |
| (2) Rates of FV           | 43         | <ul style="list-style-type: none"> <li>On average, FV appears in 10-30% of donation requests</li> <li>Stark lack of data collected on FV events in Canada</li> </ul>   |
| (3) Theory vs. Practice   | 58         | <ul style="list-style-type: none"> <li>While FV is not legally recognized in most countries, <b>in practice</b>, it is allowed almost everywhere</li> </ul>  |
| (4) Physician Duties      | 14         | <ul style="list-style-type: none"> <li>HCPs owe a duty to respect the decision of their deceased patient whenever medically feasible</li> </ul>  |
| (5) In Favour of FV       | 70         | <ul style="list-style-type: none"> <li>Family grief &amp; distress is the primary reason why FV is allowed by HCPs</li> <li>Fear among HCPs that allowing donation to proceed in the face of FV could lead to lawsuits and/or public mistrust in ODT system</li> </ul>   |
| (6) In Opposition to FV   | 61         | <ul style="list-style-type: none"> <li>Allowing FV is contrary to autonomy interests of the deceased</li> <li>FV directly leads to missed donation opportunities and harm (or death) for the would-be recipient and their families</li> </ul>  |
| (7) Proposed FV Solutions | 64         | <ul style="list-style-type: none"> <li>FV could be allowed only in narrow circumstances (ex. deceased changed their mind re: donation prior to their death)</li> <li>Public education campaigns re: communicating donation decisions</li> <li>Legal solutions: protecting donation decisions in law</li> </ul> |
| (8) Consent Systems       | 33         | <ul style="list-style-type: none"> <li>“Opt-out” consent systems <b>theoretically</b> reduce FV rates</li> <li>However, unclear which consent system best reduces FV in <b>practice</b></li> <li>Public desire for simpler consent system where donation decisions are protected</li> </ul>                    |
| (9) Law & Policy          | 64         | <ul style="list-style-type: none"> <li>Contrast between US and Canadian law – donation decisions are better protected in the US (<i>Uniform Anatomical Gift Act</i>)</li> <li>Disparity between adhering to wills vs. adhering to donation decisions</li> </ul>  |

Table 1: Main themes captured in this review

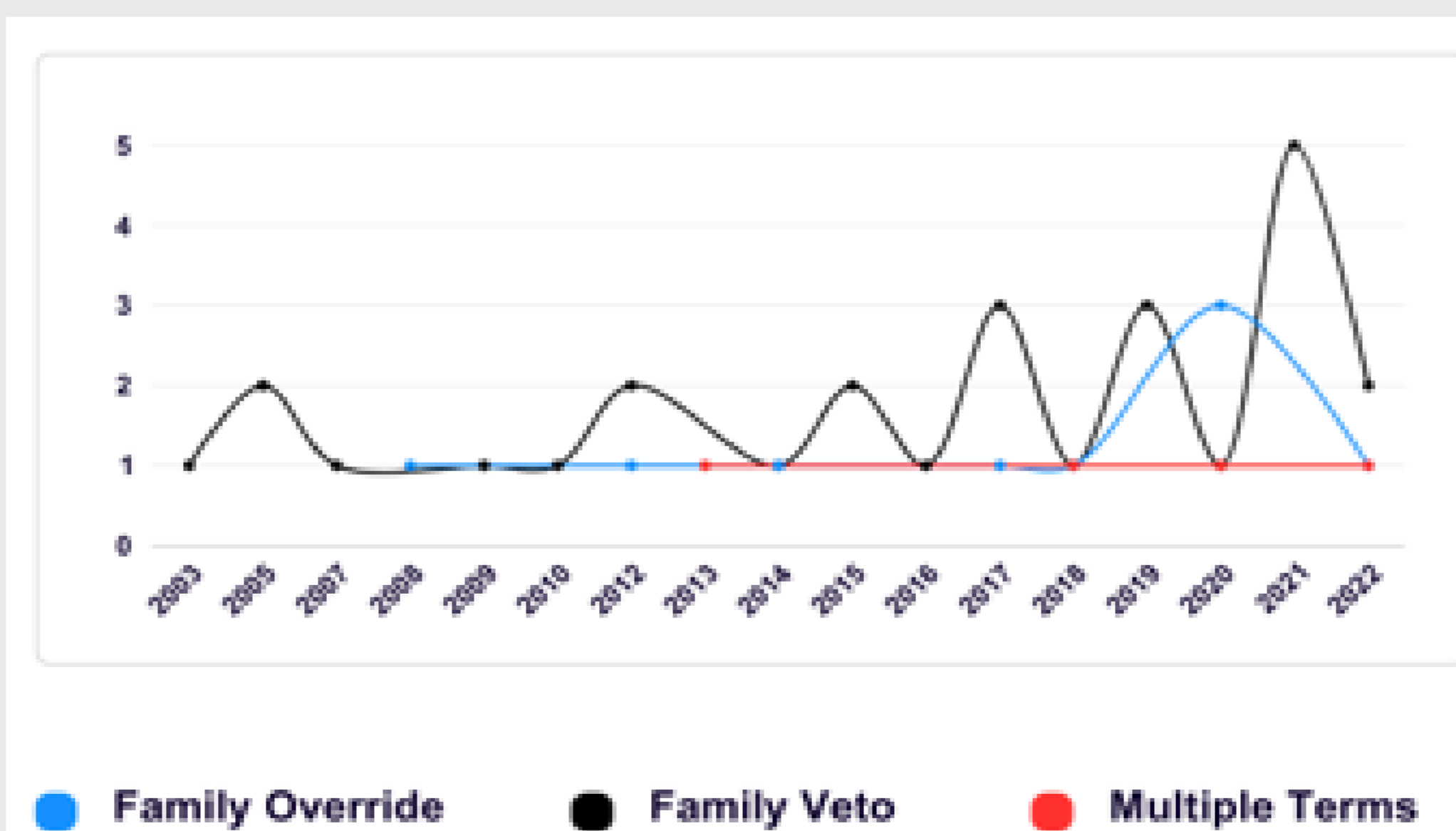


Figure 2: Rates of discussion of FV over time (2003-2022)

**NB:** This Figure only captures articles that discuss FV as a medicolegal phenomenon – the review includes other sources that describe the process of FV without naming it

**NB:** Results were collected mid-2022 (hence the sharp drop-off). It appears that additional articles on the subject have since been published

## AUTHORS

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## CONCLUSION

### Main takeaways:

- FV is harmful to donors, would-be recipients and families, and HCPs
- FV can harm donor families, who may later regret their decision
- Families are acting contrary to legal obligations by pursuing FV
- Need for OPOs and hospitals to better support HCPs in addressing FV in practice
- Need for donation decisions to be better protected by Canadian law and policy

### Gaps in the literature:

- Unclear **why** discussions of FV continue to increase – are rates of FV increasing such that the phenomenon can no longer be ignored? Or has it simply fallen into the public view given other ODT discourse?
- Paucity of data regarding the frequency of FV events in Canada
- Further research is needed to address the impact of FV on donors, families, and HCPs

### Next steps:

- Scoping review will inform SJL’s LLM thesis:
  - Is there a legal right (positive or negative) to donate organs / to have donation decisions upheld?**
  - If so, is FV a reasonable limitation on that right?**

### Questions to address include:

- What are the legal and policy ramifications of FV?
- How can the Canadian ODT system be improved to better protect patient autonomy?
  - First-person authorization legislation
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## ACKNOWLEDGEMENTS

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[1] Canadian Blood Services, “Background: National Organ and Tissue Donation Awareness Week”, <https://www.bloodservices.ca/organ-tissue-donation-2022/>.

[2] Bertram L. Loeb, “Family veto in organ donation: the experience of Organ and Tissue Donation Coordinators in Ontario”, *2021:40 Can. J. Anesth.* 611.

[3] Health Canada, “Organ Donation and Transplantation Collaboration”, (19 July 2022), <https://www.canada.ca/en/health-canada/services/health/organ-tissue-donation-organ-tissue-transplantation-collaboration.html>.

Additional sources consulted in the scoping review include:  
 Alison Stewart & Craig Brewster, “Understanding decision to respect donor autonomy: Should we nudge families to consent to organ donation?”, *2019:12 Bioethics* 105.  
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 Ian H. Dale, Bruce Chikowski & Robert Stewart, “Moral veto about the family veto”, *2007:16(8) Clin. J. Anesth.* 801.  
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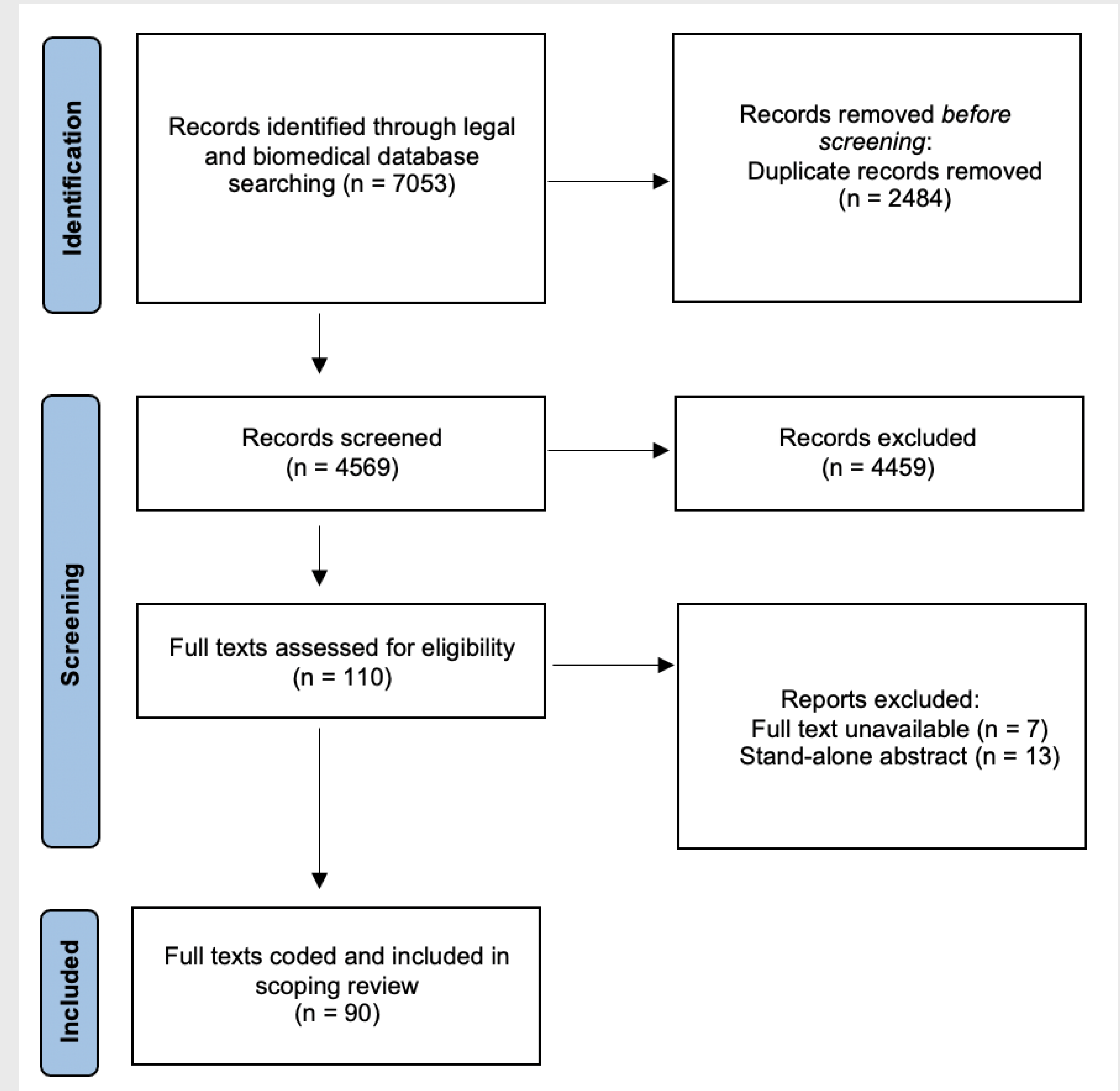


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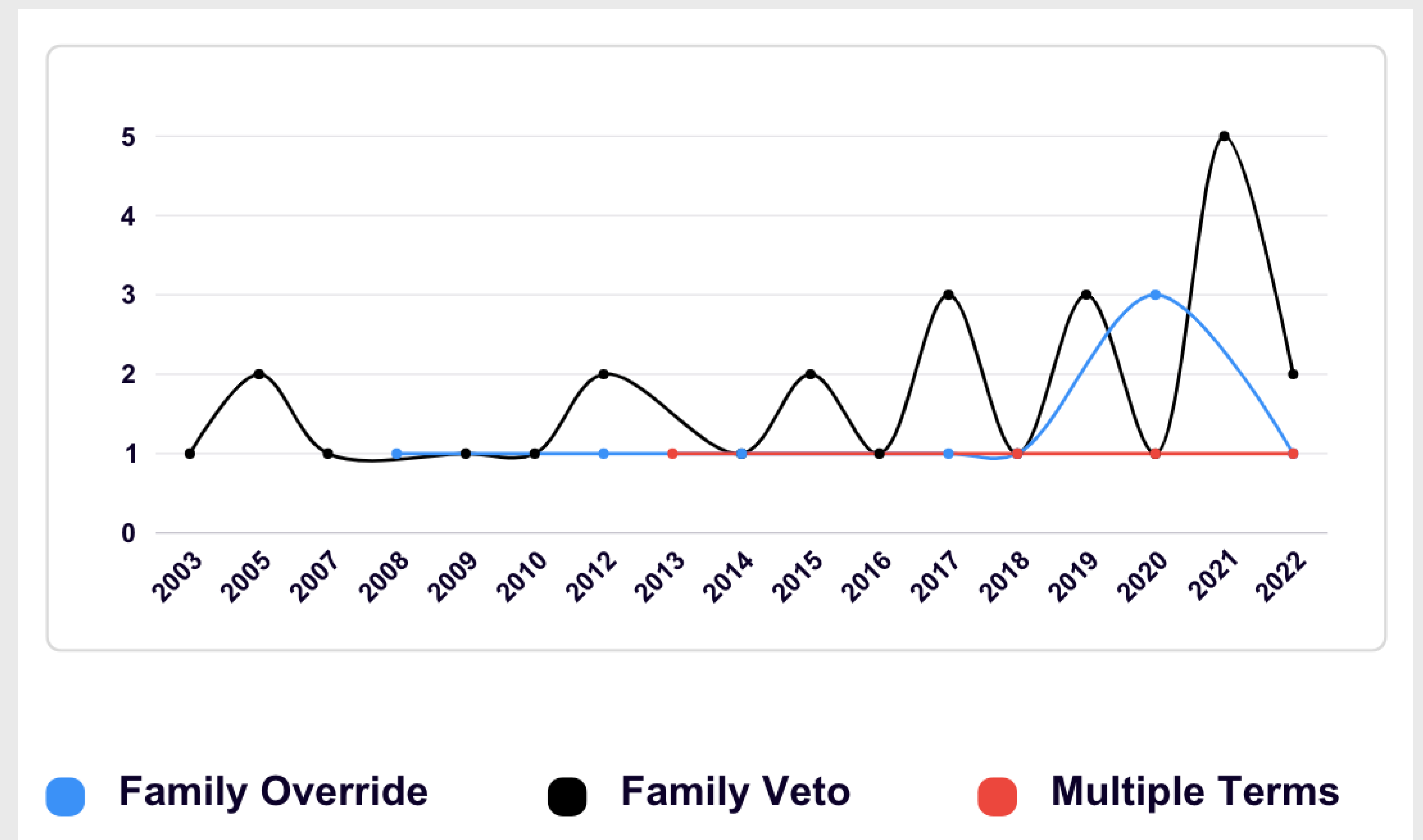


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