

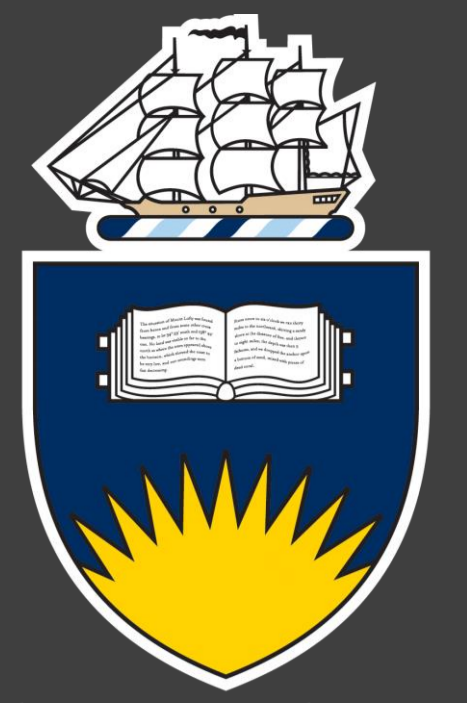


A systematic review of the public acceptability of gene therapy and gene editing for human applications

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Introduction

- Genetic technologies have advanced, and the potential human applications are expanding.
- Gene therapy and gene editing technologies are complex and can be difficult for the public to understand.
- Patient and public support are critical for successful adoption.
- The application, type of modification, and associated risks all impact people's perceptions of these technologies.
- It is critical to understand current obstacles against acceptability of genetic medicines to enable greater adoption for human use.

Aim

- To conduct a comprehensive systematic review to highlight factors that influence public perceptions and acceptability of genetic therapies.

Methods

- Databases: Ovid Medline, PsycINFO, Scopus, and Web of Science
- Search terms: [(public OR lay OR popular* OR countr* OR communit* OR patient* OR carer* OR caregiver* OR "care giver"* OR personal OR parent*) NEAR/10 (attitude* OR accept* OR opinion* OR perception* OR view* OR belief*)] AND [(gene OR genes OR genetic* OR gene-based) NEAR/1 (addition OR edit* OR therap* OR treat* OR transfer* OR repair* OR replace* OR medicine*)].
- Inclusion criteria: Full-text, English language, peer reviewed articles that presented data on people's perceptions, attitudes, opinions or views on the acceptability of gene therapy or gene editing for human use.

Common themes

- Demographics
 - Greater support from:
 - Younger individuals;
 - Males;
 - Those with better (self-reported) genetic knowledge, lower religiosity and increased trust in scientists.
- Treatment specifics
 - Greater support for:
 - Medical applications (vs non-medical);
 - Serious/fatal diseases (vs debilitating diseases);
 - Somatic therapy (vs germline therapy).
- Risks versus benefits
 - Lower perceived risks associated with:
 - Greater gene therapy knowledge/education;
 - Increased willingness to take part in trials.
 - Including the percentage likelihood of risks was helpful for participants to form their own opinions about gene therapy.
- Ethical or moral issues
 - Complex relationship.
 - Personal, societal, and environmental implications must be balanced against the potential benefit of genome modification.
- Trust, fears, or concerns
 - Issues of mistrust (of research, scientists, the medical system, government rules, and those in charge) form a barrier for clinical trial recruitment.
- Changes over time
 - 2 studies looked at actual changes over time (from 1991-2003) reporting relatively stable levels of optimism.
 - Perceptions of gene therapy were more positive in recent articles, most likely owing to the increased exposure and knowledge of the capabilities of genetic technologies.

Conclusions

- Perceptions of gene therapy are generally positive, particularly for medical reasons or fatal diseases, however these perceptions are also influenced by perceived risk.
- Somatic gene therapy or editing had higher levels of acceptability than the use of germline transgenesis.
- Over half of the papers included were published in the last 8 years, reflecting recent advances in gene therapy/editing and the increasing importance of understanding perceptions.
- Increased knowledge and awareness through specific education about these therapies can alter risk and benefit perceptions.

Recommendations

- More consistent measurement of perceptions is needed.
- Scientists need to better educate the public about the risks and benefits of these technologies in a simple and understandable way for improved public knowledge and acceptability.

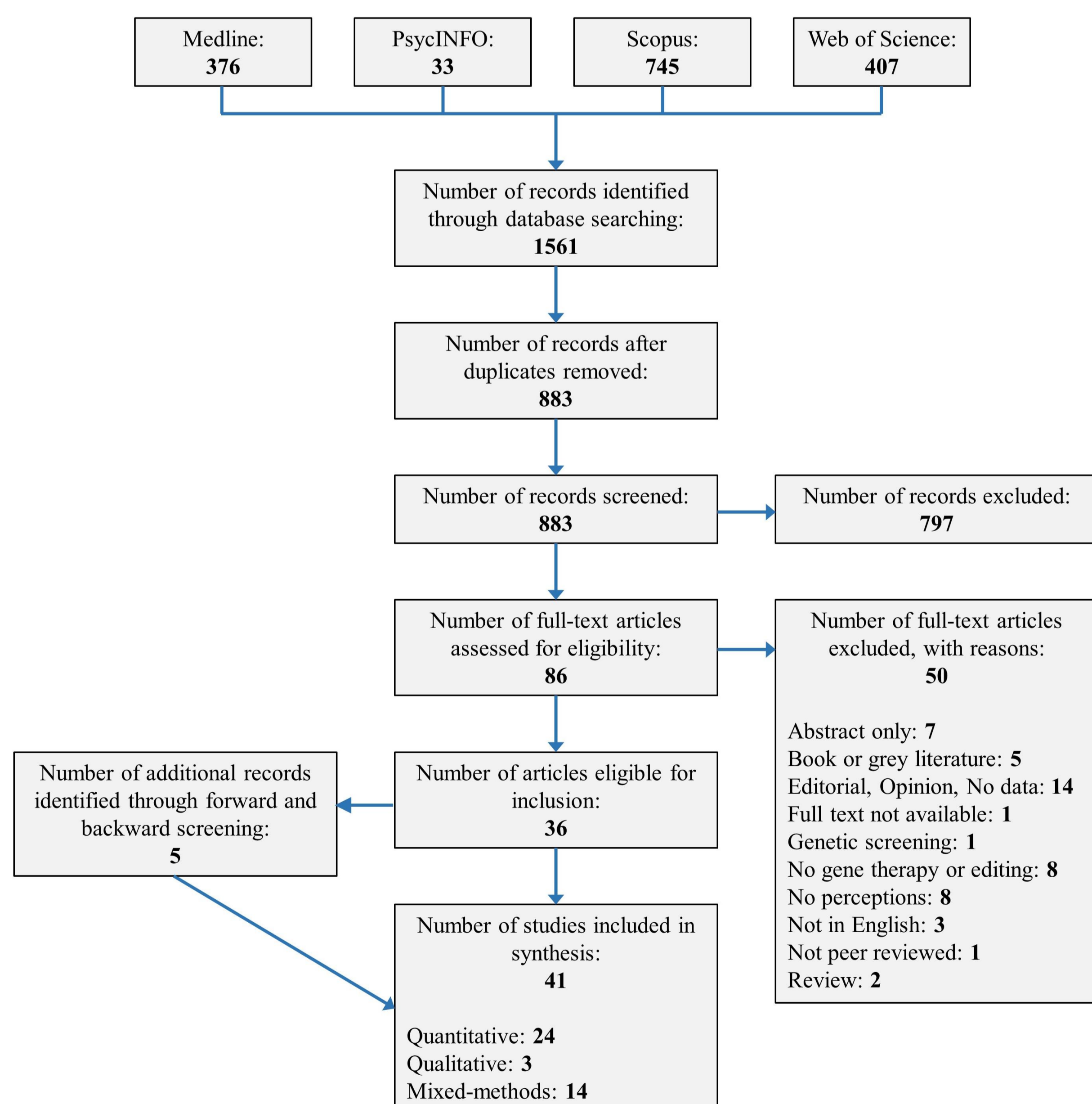


Figure 1: PRISMA flow diagram of study selection identifying the number of studies from each source, the number and reason for excluded articles, and the of types of data contained in full-text articles included for final review.

Study characteristics

- 24 quantitative, 3 qualitative, and 14 mixed-method studies.
- Published from 1992 to 2019.
- The number of participants ranged from 22 to 13,201.
- Ten studies (2016-2019) specifically examined gene editing.
- 23 were medium quality, 9 high quality, 9 low quality.

