Dalla Lana
School of Public Health

ResearchWaste.info: Raising Awareness of Avoidable Waste in Health Research

Pavel Zhelnov, MD

PhD Supervisor: Dr. Andrea Tricco
Committee: Drs. Sharon Straus & David Moher
Patient Partner: Lisa Ridgway, JD

…and at least 56 collaborators, reviewers, peers, instructors, community members…

Institute of Health Policy, Management and Evaluation
UNIVERSITY OF TORONTO

Positionality & Conflicts of Interest

CIHR's Strategy for Patient-Oriented Research (SPOR):

"Patients need to be involved in all aspects of research to ensure questions and results are relevant"

Our Vision – SPOR Evidence Alliance:

To promote a Canadian health system that is increasingly informed and continuously improved using up-to-date scientific evidence.

Experience:	MD (2017, St. Pete, Russia), Orthopaedic Surgery (2020), Policy Analyst (2022)
Program:	PhD in Health Systems Research (2023–2027, IHPME)
Emphasis:	Organization & Management, Collab Specialization in Global Health
Funding:	IHPME Funding Package, SPOR Evidence Alliance Grants, SDGs@UofT 2024 Student Award

Background – Declaration of Helsinki 2024

wma.net/policies-post/wma-declaration-of-helsinki/

Scientific Requirements and Research Protocols

21. Medical research involving human participants must have a scientifically sound and rigorous design and execution that are likely to produce reliable, valid, and valuable knowledge and avoid research waste. The research must conform to generally accepted scientific principles, be based on a thorough knowledge of the scientific literature, other relevant sources of information, and adequate laboratory and, as appropriate, animal experimentation.

    The welfare of animals used for research must be respected.

What is (health) research waste? Working definition

- Research found **unhelpful** by other researchers or knowledge users.
- A knowledge user is anyone who is "likely to be able to use the knowledge generated through research in order to make informed decisions" (CIHR).
- Exclusive of outright misconduct (falsification, fabrication, plagiarism) but taps into "questionable/unacceptable research practices" (p-hacking, "spin").
- A failure on part of "individuals, teams, and organizations involved" in research to implement the "design and execution that are **likely** to avoid":

MINUS
framework for research waste

(Rosengaard et al., 2024)

- **M**ethodological flaws
- **I**nvisibility
- **N**egligible research
- **U**nderreporting
- **S**tructural barriers

85%

(Glasziou, Chalmers, 2016)

Methods – Thesis design

Canadian Institutes of Health Research | Instituts de recherche en santé du Canada

PROTECTED WHEN COMPLETED

Appl. #	

Aim 1. Scoping review: Systematically map RW studies and tools to identify methodological gaps.

Aim 2. Key informant interviews & focus groups: Collect input on RW assessment needs from researchers and knowledge users (KUs) such as patient partners, healthcare providers, and policy-makers.

Aim 3. Tool development & pilot testing: Integrate findings from Aims 1–2 to develop a RW decision tree and guide, and test the tool on research outputs of the Strategy for Patient-Oriented Research (SPOR) Evidence Alliance (SPOR EA), a pan-Canadian CIHR-funded initiative designed to reduce RW.

Expected Outcomes: A RW tool for researchers and KUs, available online for free in interactive and printer-friendly formats, and in multiple languages (English, French, Chinese, and others).

Methods – Knowledge mobilization

Scoping Review

721 records
442 screened
6 abstracted

Living Search

4163 articles found
2–3 new/week

Community Engagement

356 website visits
5927 LinkedIn views

Newsletters

Featured in:
SPOR Evidence Alliance
Centre for Global Health

Top Sectors

Healthcare (23%)
Research (16%)
Education (12%)

Top Locations

Toronto, Ontario (20%)
Copenhagen, Denmark (8%)
Vancouver, British Columbia (7%)

Face-to-face Talks

60 individuals: trainees, faculty, patient partners, admin staff

ResearchWaste.info

85% – Ep. 1

85%

Share

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Welcome

AWARE is a scoping review of Avoidable WAste in REsearch and a tool in development to inform academics, clinicians, patient and public partners, policy-makers, journal editors, and funders on how to reduce research waste in health and biomedical sciences.

Contribute

Help improve this doctoral research project at the University of Toronto and the SPOR Evidence Alliance. We will acknowledge all contributions in the final report.

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Results – Preliminary findings

Research waste assessment methods:

⚠️ **Are variable**
across studies

❌ **Are poorly reported**
in meta-research

❌ **Cover limited aspects**
of research waste

❌ **Lack comprehensive,**
user-friendly tools

❌ **Particularly problematic for**
patient and public partners

Conclusions – Expected impacts

- **An evidence-informed tool to "run" health research protocols & reports.**
- Available online for free as an interactive app and a printer-friendly PDF.
- Intended for patient partners, the public, academic reviewers (peer, editorial, funding), healthcare professionals, and policy-makers.
- Supports decision-makers by informing them about the research waste potential before, during, and after doing the study.
- **Features:**
  - Aims to incorporate all published research about research waste to date;
  - Piloted by 10–15 diverse users and on 300+ reports at the SPOR EA;
  - Developed using reproducible methods – can be updated/customized;
  - Multiple languages: English, French, Chinese, and others.
- **Examples of similar tools:**
  - INQUIRE (content): https://doi.org/10.1371/journal.pmed.1002580
  - Right Review (design): https://whatreviewisrightforyou.knowledgetranslation.net/

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Thank You!

Supplemental slides

Methods – Overall goal

- The overall project goal is to develop and pilot-test an online interactive tool for evaluating **research waste** in **health research** to empower researchers, patients, and other **knowledge users** (clinicians, trainees, policy-makers, administrators, funders, journal editors, and the public) to make **evidence-informed** decisions involving health research.

- "Evaluation" and "assessment" are used interchangeably because the distinction is applied inconsistently in interdisciplinary practice (e.g., assessment vs. evaluation in education *cf.* outcome assessment, economic evaluation in health sciences).

- "Evidence-informed" is intended to represent a relaxed version of "evidence-based", meaning reliance on knowledge synthesis of empirical (field) quantitative, qualitative, or mixed-methods research.

Methods – "Scope creep" issues

- As a meta-research project, this addresses all four pillars of health research as defined by CIHR, including:
  - Biomedical research
  - Clinical research
  - Health services research
  - Social, cultural, environmental and population health research

- However, as an adopter of patient-oriented research, integrated knowledge translation, and user experience methods, I recognize that an "all size fits all" approach is not likely to enable meaningful use of the tool in practice.

- I address this conflict by applying a dialectical critical realist lens that suggests that both general and context-specific insights are important.

Biomedical research (Pillar 1)

Biomedical research focuses on understanding how every part of the human body works—right down to our cells.

By studying these workings at the molecular, cellular, organ system, and whole-body levels, biomedical research leads to new ways of diagnosing, preventing, and treating illness and disease.

Clinical research (Pillar 2)

With the help of volunteer participants, clinical research leads to new and improved:

- Medications, vaccines, therapies and treatments
- Medical tests, procedures and practices
- Medical tools, equipment and devices
- Scientific knowledge and understanding of illness and disease

Health services research (Pillar 3)

Health services research focuses on improving health care for everyone.

By studying how health care services are organized, supported, and delivered across Canada, we can make the overall system better.

This research generates information to help enhance care for patients, reduce costs, and address the needs of health care providers.

Social, cultural, environmental and population health research (Pillar 4)

Social, cultural, environmental, and population health research aims to improve the health of entire communities.

There is more to your health than meets the eye! This type of research uncovers the ways that social, cultural, environmental, occupational, and economic factors can affect it—for better or for worse.

Methods – Self-evaluation of research waste (MINUS-ES). Slide 1 of 3. Version: 2025-05-05

- **Methodological**: Experienced team, follow conduct guidelines (e.g., JBI Manual for scoping reviews). Inclusive design (mixed methods).
- **Invisible**: Integrated knowledge translation from Day 1, ongoing community updates (website, social media). Intend to register and publish protocol.
- **Negligible**: Rapid scoping review and living search updates at protocol stage, including registers (OSF) and novel technologies (“deep research”). Collaboration with “academic competitors” (Rosengaard, Moher). Open discussion on social media (INQUIRE).
- **Underreported**: Follow relevant reporting guidelines (PRISMA-ScR, COREQ, GRAMMS, FAIR). Check reproducibility whenever possible. Establish channels for public and private feedback.
- (*continued*)

Methods – Self-evaluation of research waste (MINUS-ES). Slide 2 of 3. Version: 2025-05-05

- (*continued*)
- **Structural**: Research conducted at a centre familiar with and embracing intended research methods (Knowledge Translation Program, SPOR EA, University of Toronto), with funding and supports available. High-income country setting. Diverse interdisciplinary team, personal contacts. Internet technologies for global reach-out (machine translation, social media). Funding applications as a way to obtain external feedback. Patient partner collaboration.
- **Emergent**: Periodic AI peer review of protocols and manuscripts to identify additional issues. Existing tools identified (INQUIRE) – iterate and revise thesis design to keep the project relevant.
- **Summative**: (*continued*)

Methods – Self-evaluation of research waste (MINUS-ES). Slide 3 of 3. Version: 2025-05-05

- (*continued*)
- **Summative**: Generated using Claude 3.7 Sonnet, user prompt.
- “This project displays concerning deficiencies despite superficial adherence to methodological rigor. While experienced personnel are involved, the reliance on "mixed methods" suggests potential methodological overreach without clear justification for this approach. The "invisible" components reveal an overly optimistic view of knowledge translation effectiveness---website updates and social media posts often fail to reach key stakeholders and represent checkbox activities rather than meaningful engagement. The "negligible" section is particularly troubling, as it emphasizes technological solutions ("deep research") without defining their validity or reliability. Collaboration with known researchers appears more networking-oriented than scientifically necessary. The reporting guidelines mentioned under "underreported" represent the bare minimum expectation rather than exceptional practice, and the vague promise to "check reproducibility when possible" indicates no concrete reproducibility plan exists. The "structural" advantages listed reveal troubling privilege biases---high-income setting, personal contacts, and technological dependencies that may systematically exclude important perspectives. Machine translation for "global reach-out" demonstrates naivety regarding cross-cultural research validity. Finally, the "emergent" section's reliance on "AI peer review" suggests a dangerous overconfidence in unproven technologies and potential abrogation of human critical thinking. Overall, this project requires substantial redesign to address these fundamental flaws before proceeding.”