Research Methodology

Study Type

Ethical Review Protocol — Pre-registration and ethics submission for a community-based intervention study, following IRB/HREC requirements.

Design

Three-phase pilot study:

1. **Observational baseline**: Document current emergency response times
2. **Intervention**: Deploy proximity alert system in consenting community
3. **Comparative analysis**: Measure outcomes against baseline

Rigor Level

Protocol, not data. This is the ethics submission that enables data collection. The research itself follows RCT principles adapted for community intervention.

Study Design

Phase 1: Observational

- Document current emergency response times (baseline)

- Map existing community volunteer networks
- Establish pre-intervention metrics
- **Duration**: 3 months
- **Data**: Time-to-response, outcome severity, resource utilization

Phase 2: Pilot Intervention

- Deploy proximity alert system in willing community
- Verified responders receive location-masked alerts
- Measure response times, health outcomes, participant experience
- **Duration**: 6 months
- **Sample**: ~500 households, opt-in

Phase 3: Analysis

- Compare intervention period against baseline
- Identify implementation barriers and facilitators
- Document lessons learned for scale-up
- **Primary endpoint**: Time to first-responder contact
- **Secondary endpoints**: Health outcomes, participant satisfaction, false positive rate

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Ethical Considerations

DOMAIN	PROTECTION	IMPLEMENTATION

Privacy	Location data for emergency use only	Pseudonymization, edge processing, no persistent tracking
Consent	Opt-in with training requirement	Informed consent + competency verification
Equity	Coverage across demographics	Stratified recruitment, accessibility analysis
Safety	Professional backup always available	Dual dispatch, never replace formal services
Withdrawal	Right to exit at any time	One-tap deactivation, no penalty

The Bureaucratic Barrier

The Title's Meaning

"Why Should It Cost So Much To Do Something Normal?" reflects a documented phenomenon:

WHAT WE'RE TESTING	ETHICAL RISK LEVEL	BUREAUCRATIC BURDEN
Can trained neighbors help faster?	Minimal (backup always available)	Full HREC review, 6-12 months
Existing programs (PulsePoint, GoodSAM)	Already operational	None (commercial)

The same intervention deployed commercially requires no ethics review. Studied academically, it requires months of bureaucracy.

The Cost

- **Direct**: Application fees, researcher time, consultant fees
- **Indirect**: Delay in evidence generation, continued preventable harms
- **Systemic**: Disincentive for beneficial research

Directory Structure

```
ethics_submission/
├── README.md                    # This file
├── manuscript/
│   └── paper.tex                # Ethics submission (LaTeX)
├── data/
│   └── raw/                     # (Empty - awaiting approval)
├── references/
│   └── bibliography.md          # IRB literature, precedents
├── results/
│   └── figures/                 # (Pending)
└── src/
    └── templates/               # IRB forms, consent documents
```

Key References

Ethics Review Literature

Emanuel, E.J., Wendler, D. & Grady, C. (2000). What makes clinical research ethical? *JAMA*, 283(20), 2701-2711.

Schrag, Z.M. (2010). *Ethical Imperialism: Institutional Review Boards and the Social Sciences*. Johns Hopkins University Press.

Precedent Programs

Brooks, S.C. et al. (2016). PulsePoint AED alerts and bystander defibrillation. *Circulation*, 134(Suppl_2), A17411.

Smith, C.M. et al. (2020). GoodSAM smartphone app and bystander response. *Resuscitation*, 154, 89-96.

Related Studies

THIS STUDY	CONNECTS TO	LINK
Research enabled	emergency_response	../emergency_response
Alert system design	direct_personal_alerts	../direct_personal_alerts
Mathematical model	mathematical_foundations	../mathematical_foundations
Public framing	anchor_wellbeing	../anchor_wellbeing

Closes Escape Route

"We need more research before acting"

This submission documents that the barrier to research is not scientific uncertainty but bureaucratic friction. Programs achieving the same outcomes commercially face no such barriers. The escape route of "we need research first" is invalidated by the observation that research itself is blocked, while unresearched deployment proceeds.

Evidence Strength

CLAIM	EVIDENCE LEVEL	CONFIDENCE
Proximity response is faster	Strong (PulsePoint/GoodSAM data)	High
Ethics review delays beneficial research	Moderate (documented delays)	Moderate
Bureaucratic friction is systematic	Observational	Moderate
Pilot study will generate useful data	Projected	N/A

Status

- **Protocol**: Complete
- **Ethics submission**: Awaiting institutional review
- **IRB templates**: Available in `src/templates/`
- **Timeline**: 6-12 months expected for approval

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