Towards a better health technology innovation system:

A scoping review of patient and public involvement in technology development & technology assessment

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INTRODUCTION

PPI in HTI

Health Technology Innovation (HTI)

- Technological innovation in health (e.g., drugs, devices, ICT, diagnostics) should ….
  - Improve outcomes & support quality, coordinated care, and equitable and sustainable health systems
  - Serve patients and publics
- Important advances, and many limitations
  - “Me too” technologies & unmet needs
  - High costs, many marginal benefits & considerable uncertainty
- Responsible innovation
  - Patient & public involvement as partial remedy?

PPI in Health technology innovation

PPI in Health Research

- Inform priorities
- Inform research design; data collection; data analysis
- Support KT

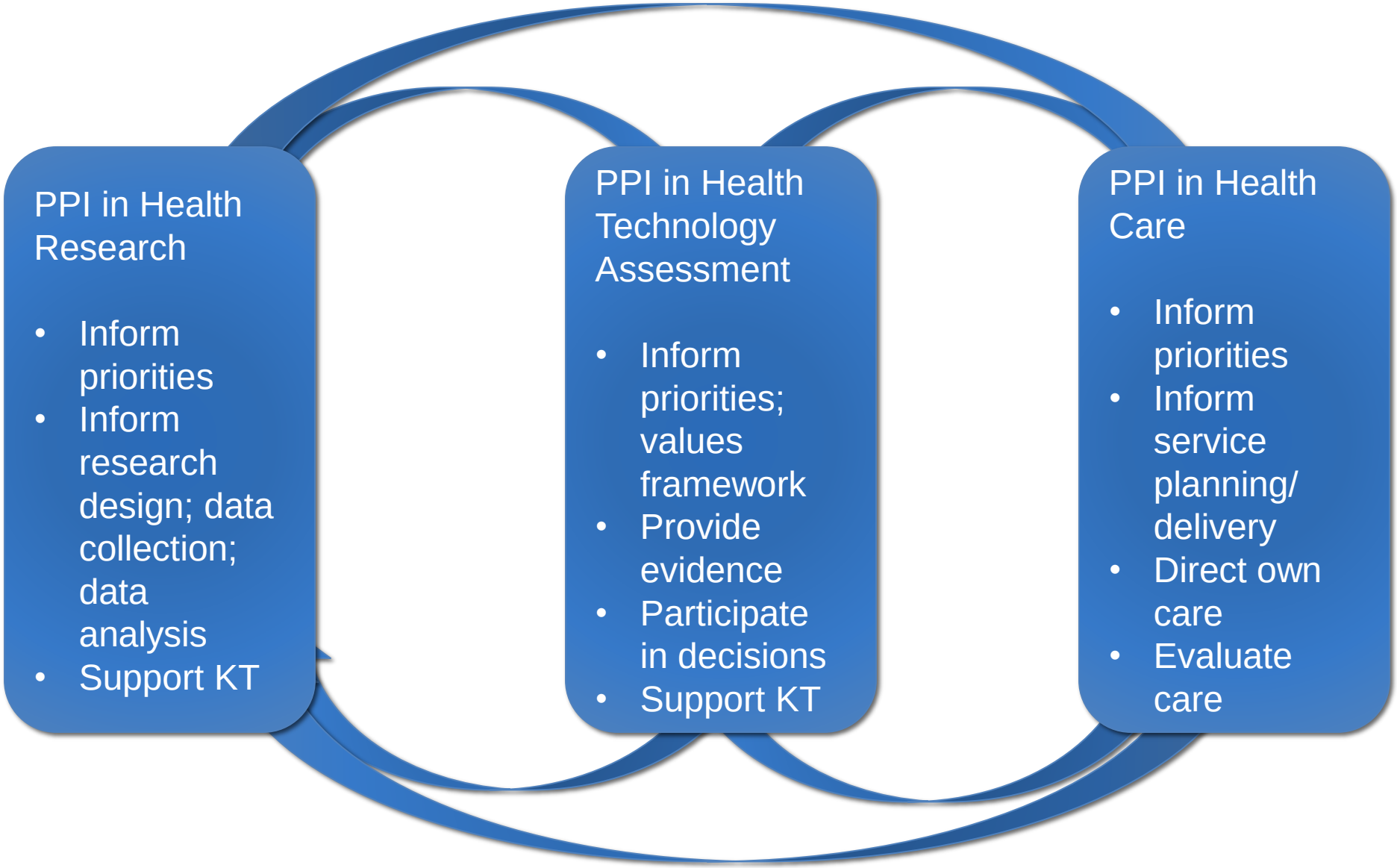
PPI in Health Technology Assessment

- Inform priorities; values framework
- Provide evidence
- Participate in decisions
- Support KT

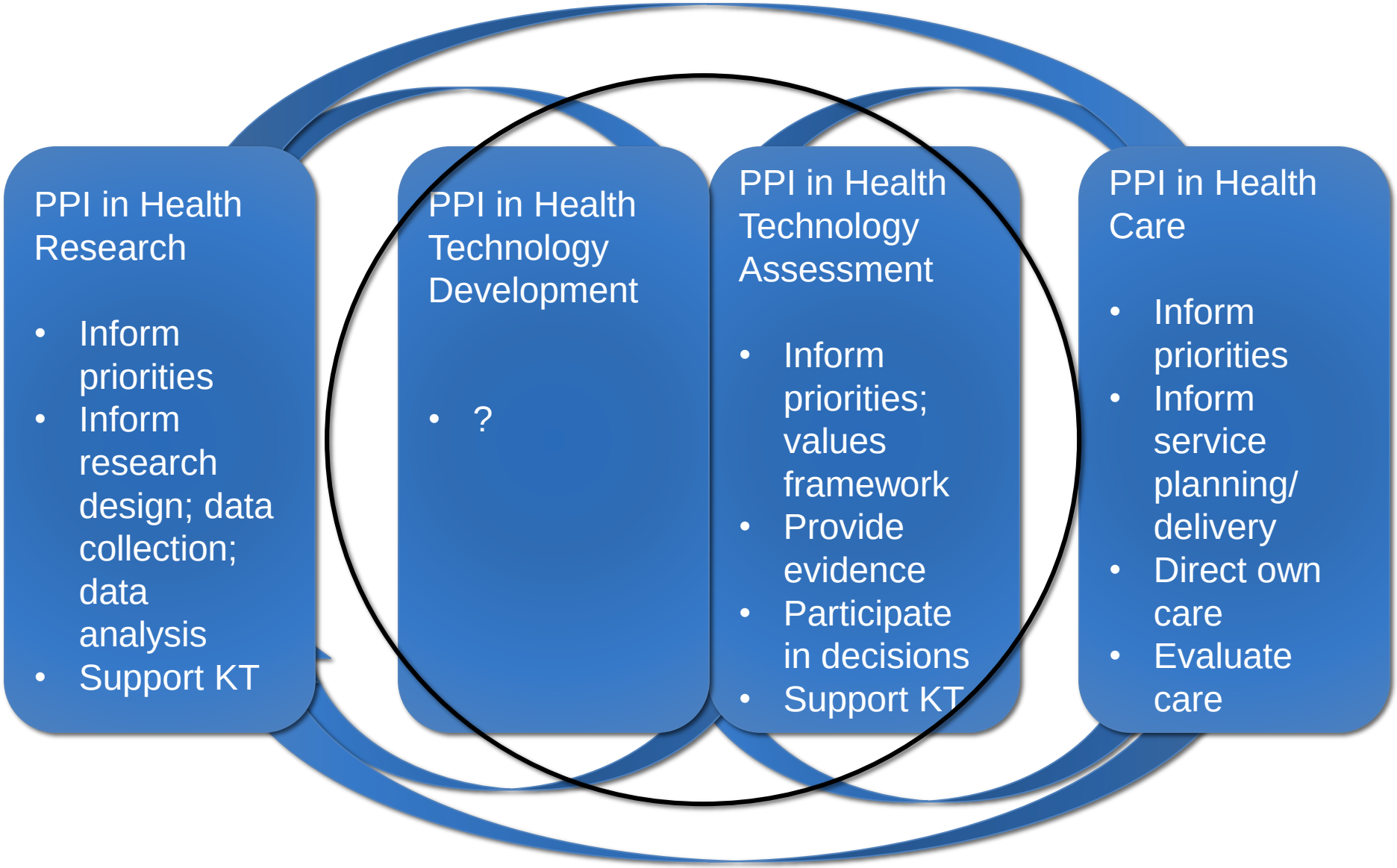
PPI in Health Care

- Inform priorities
- Inform service planning/ delivery
- Direct own care
- Evaluate care

PPI in Health technology innovation **system**



PPI in Health technology innovation **system**



METHODS

PPI in HTI

Methods

- Scoping review of published literature
  - As proposed by Arksey & O'Malley (2005) and Levac et al. (2010)
- Scoping reviews aim to '**map**' key concepts underpinning research area, and main sources and types of evidence
  - Includes a diverse range of literatures e.g., conceptual, empirical (including qualitative and quantitative), and grey literature
  - Does not assess quality or exclude studies on that basis
- "**Compass**" question, and iterative search & selection process (Eakin & Mykhalovskiy, 2003)

Search strategy

- Overarching interest in PPI within health technology innovation systems

- After initial review of literature, refined question and added specific objectives :
  - What is the role of PPI in **Health Technology Assessment** (**HTA**) and **Health Technology Development** (**HTD**)?
    - Why do HTA agencies and industry pursue PPI?
    - How do HTA agencies and industry pursue PPI?
    - How similar or different are HTA agencies and industry (and **across industries**) in intentions and approaches to PPI?

Database search

- The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) criteria used to guide conduct and reporting (Moher et al, 2009)
- 4 reference databases searched, from 1980 to 2014:
  - Medline, CINAHL, Embase and Econlit (Proquest)

- Search criteria:
  - Population of interest (patients, the public and synonyms)
  - Primary activity (involvement/engagement and synonyms)
  - Context (HTD and HTA)
  - Health technology product (device, drug or diagnostic and synonyms)

Selection

- Search strategy implemented, January 24, 2014 to April 23, 2014
- Title and abstracts independently screened by two reviewers (AN, FD)
- Full texts assessed for eligibility for final inclusion by one reviewer (AN, FD, or SJP)
- Final decisions on inclusion made through discussion with fourth reviewer (FAM)
- Reference lists were reviewed for key or frequently cited papers not captured by the database search
  - Reviews excluded; relevant citations included

Data analysis

- All included articles read in full and summarized using standardized approach to capture publication year, methods and key findings
- A qualitative interpretive approach
  - Thematic analysis using techniques of constant comparison (Thorne, 2000; Glaser and Strauss, 2009; Charmaz, 2006)
  - Informed by "logics" for mixed methods-mixed research synthesis (Sandelowski et al, 2012)
    - *Assimilation* by aggregation of similar findings, irrespective of method or aim or original source
    - *Configuration* by linking of dissimilar findings to identify new patterns or relationships

RESULTS

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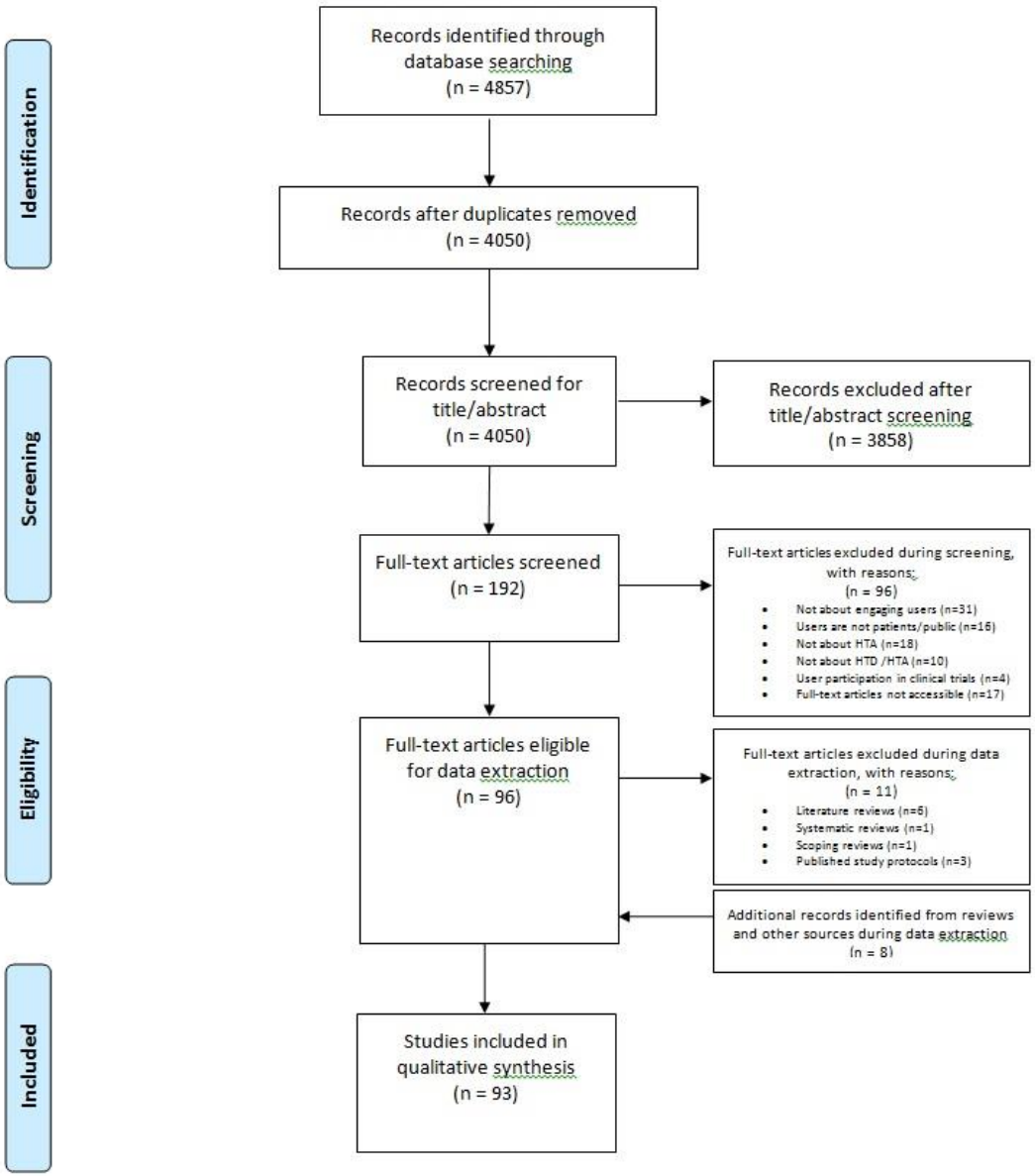
PRISMA Flow Diagram



Results

- 4,050 unique records identified across 4 databases
- 93 articles included in our analysis
  - 65 (70%) published > 2005
- 61 (65%) concerned with Health Technology Development
  - 54 from medical technology industry, defined broadly
  - 7 from pharmaceutical industry
- 32 (45%) concerned with Health Technology Assessment

- 56 (60%) used empirical research designs

- 6 Themes

"Patient or public" to engage

- HTD – Engage Patients
  - Medical technologies engage "end users"
    - Typically engage patients when used by patients not when used on or used for patients; though some broader focus
    - Others, e.g., clinicians, may also advise on user needs
  - Pharmaceuticals engage "patient groups"
    - "understanding what it means to live with the illness"
- HTA – Engage Patients & Publics
  - Patients: "first hand experiences," "values and expectations"
  - Publics:
    - "expertise of the community as a whole"
    - "potential recipients"

Goals of engagement – Understanding demand

- HTD
  - Medical technologies – to assess “usability”
    - To make better - safer, more effective, easier to use
  - Pharmaceuticals
    - To understand or consider needs and priorities
- HTA
  - Patients
    - To align HTA recommendations with values and needs
    - To select priorities and refine topical foci
  - Publics
    - To gain insight and guidance on values

Goals of engagement – Facilitating acceptance

- HTD
  - Medical technologies
    - To facilitate uptake or sales
    - To facilitate adherence and avoid failure and abandonment
  - Pharmaceuticals
    - To facilitate technology reimbursement or pricing decisions
- HTA
  - To make complicated decisions more accessible
  - To build understanding and support for recommendations
  - To make processes more fair and legitimate

Challenges of engagement – Resource challenges

- HTD
  - Medical technologies
    - Timing, participant availability, training needs and cost requirements of engagement
    - Concerns about implications for timely and affordable development
  - Pharmaceuticals – NA
- HTA
  - Timing, participant availability, training needs and cost requirements of engagement
  - Concerns about implications for timely and affordable assessment

Challenges of engagement – Epistemic challenges

- HTD
  - Medical technologies
    - Limitations seen to reside in “users” – unable or unwilling to articulate needs
    - Limitations seen to reside in developers – uncertainty or disparagement
  - Pharmaceuticals – NA
- HTA
  - Attitudinal challenges among specialists vis input from patients/ publics

Orientation to “the other”

- Papers concerned with technology development evince awareness of mechanisms for collective decision making on adoption
  - Not HTA specifically
- Less awareness in HTA literature
  - Though brief mention that PPI might be relevant in technology design or development

DISCUSSION

PPI in HTI

Key lessons

- Two solitudes
  - HT Development and HT Assessment as isolated institutions, acting “independently”
- Some similarities
  - Resource and epistemic challenges in PPI
- Key differences
  - Who to involve
    - Patients and Publics (HTA) not just Patients (HTD)
    - Patients as distinctive expertise (HTA)
  - Why to involve
    - Engagement to address values and needs (HTA) and sustain use (HTD-MT), not just foster sales (HTD-P)
    - Engagement to foster legitimacy (HTA) not to enroll allies (HTD-P)

Conclusions

- Emphasize best from all
  - Public as essential stakeholder
  - Patient as distinctive expertise
  - Engagement as partnership

- Build on this
  - Awareness of wider system, and system effects, within each institution
  - Expanded “responsible innovation” approach to PPI

Thanks!

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