
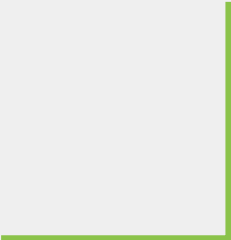


Identifying Gaps in Patient-Centered Research of Justice Involved Populations



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Background

- The United States spends more money on healthcare and incarcerates a higher number of persons than any other country in the world.
- Negative health effects related to incarceration include:
 - Infectious diseases (HIV, TB);
 - Differential access to health care services -> delays in diagnosis and treatment;
 - Restrictive prescribing practices.
- Health outcomes and negative effects are related to the demographic characteristics of those involved.

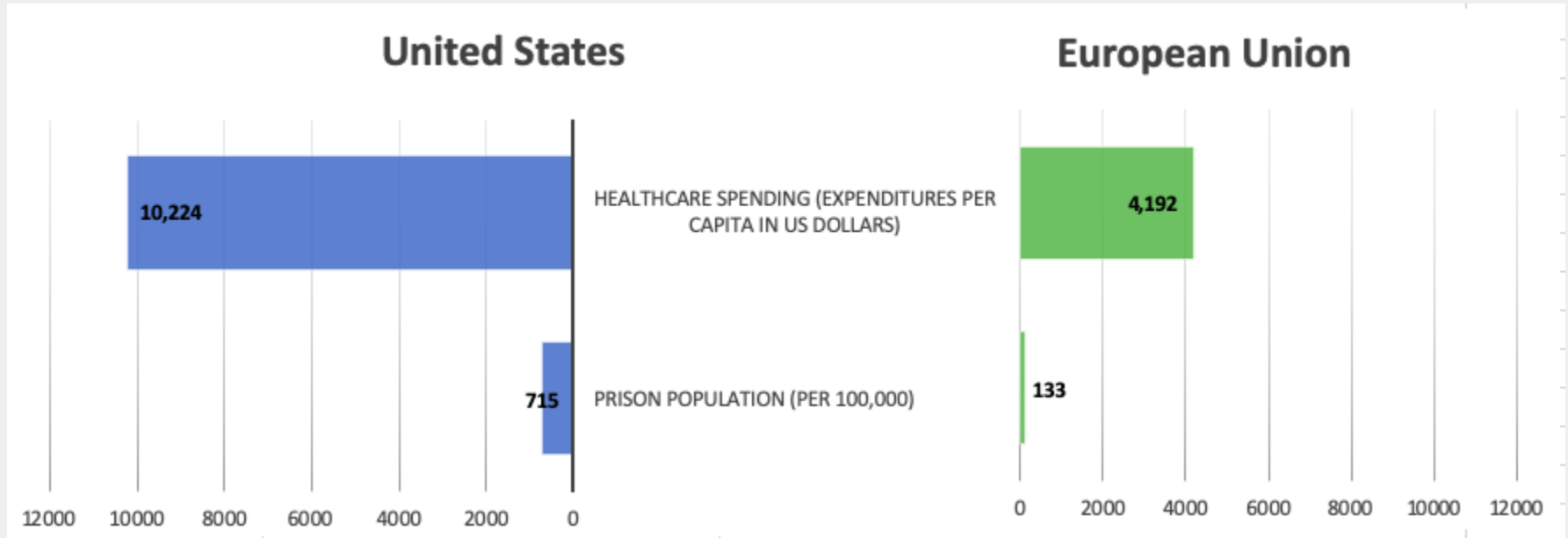


Figure 1: Comparison of Incarceration rate (per 100,000) and per capita healthcare spending (in US Dollars) between the United States and the European Union as of 2017 ([International Centre for Prison Studies, 2018](#); [OECDiLibrary, 2018](#)).

Research Involving Incarcerated Populations

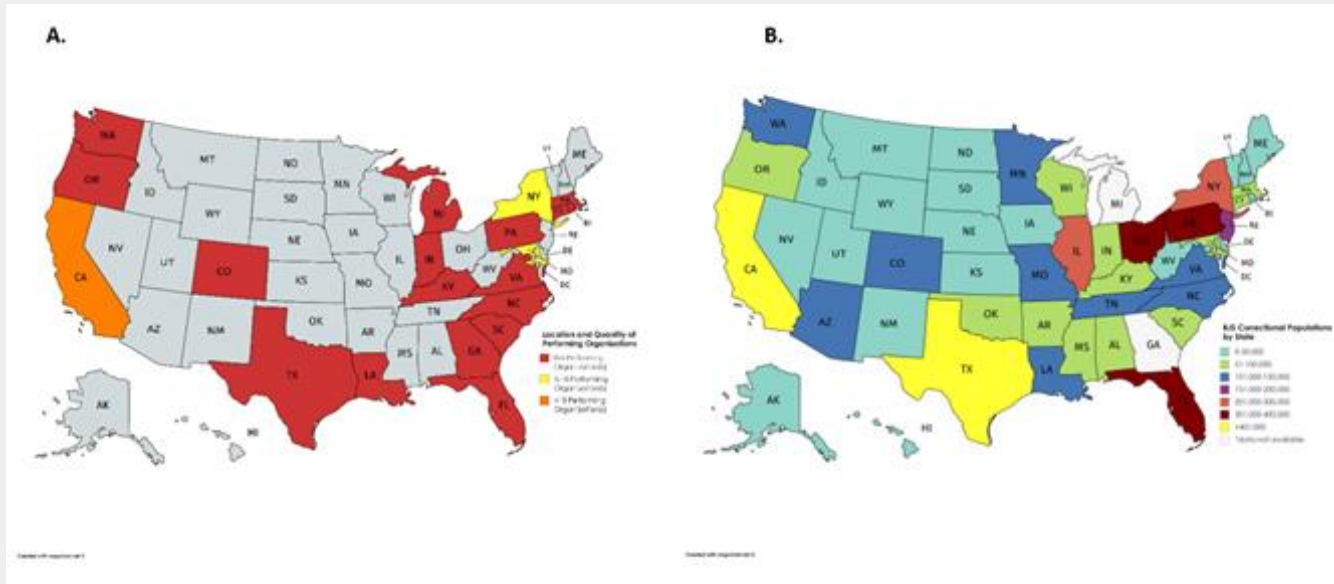
- Classified as a vulnerable population and researchers are subject to intensive IRB oversight.
- Possibility of the Hawthorne Effect.
- Incarcerated/justice-involved persons may participate for social interaction or may be very hesitant/cautious.
- No difficulties should negate the value of participant involvement in research

Hypothesis

Health services research incorporating patient-centered or patient-engaged methodologies would be underrepresented in the justice-involved population and reflected in the HSRProj full data download.

Methods & Results

- Advanced search performed using HSR Abstracts:
 - Prison “OR” prisons “OR” prisoners “OR” incarceration “OR” justice “OR” detention “OR” parole “AND” gaps
 - Yields N=71 Studies
- MeSH filtered for: patient participation (n=6) and quality of life (n=2)
- Additional search performed using PubMed research database.
 - MeSH terms: prison, prisons, prisoners, jail, incarceration, detention, parole, patient participation.
 - n=3 studies conducted within the last 10-years.
- Bureau of Justice Statistics (BJS) database (updated April 2018) utilized to identify correctional populations.



The total correctional population in the U.S. as of December 31, 2016 was 6.6 million [320,000 federal & 6.262 million state).

Figure A. represents the location and quantity of performing organizations & **Figure B.** is the U.S. correctional population by state in 2016 as reported by BJS in 2018.

Methods & Results 2.0

- Performed advanced search of KeyWordList:
 - Contains prison “OR” prisons, prisoner “OR” incarceration, jail “OR” detention, justice “OR” parole
 - N=186 search results -> filtered for duplicates & selected for U.S. only studies -> N=95 remaining.
- Filter of N=95 studies for terms related to patient participation in research/relating to CBPR (n, % of N=95)
 - CBPR (1, 1.05%);
 - Community action (0);
 - Participatory action research (0);
 - Community based action research (0);
 - Participatory rapid appraisal (0);
 - Empowerment evaluation (0);
 - Quality of life (7, 7.37%);
 - Patient-centered (6, 6.32%); and
 - Self-report (6, 6.32%)

Conclusions & Recommendations

- Studies that involve incarcerated populations and use methods of patient-reported measures are rare in the current literature.
- Two rounds of search methodologies using both the HSRProj database & PubMed exhibited gaps in research of incarcerated populations centered around patient participation.
- States with the highest incarceration rates are not being studied by researchers in their proximity.
- The prison population is distributed across the US, but that is not reflected by the organizations conducting research.
- Research that engages the incarcerated population and uses patient-reported measures to explore quality-of-care and health outcomes would be instrumental in filling current gaps in the literature.

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