Development of an ethical framework to support nurse-led healthcare research with prisoners

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Aim of presentation

- Prison setting and health
- Need for health research in the prison setting
- Ethical implications
- Experiences
- How to proceed
Background

- Older prisoners are the fastest growing group in the prison population
  - Those over the age of 60 have increased by 120% in a decade

- Accelerated aging
  - Prisons health is 10 years older than that of their community dwelling counterparts

- Higher risk of chronic diseases
  - 71% of prisoners between 50 – 54
  - 92% in those over the age of 70
Background

- Comparable to community dwelling adults prisoners have higher incidences of:

  - Hepatitis C
  - Cardiovascular disease
  - Substance use disorders
  - Mental illness

  - Silva et al. (2017)
Dementia in Prison

- Higher risk of dementia due to poor health
  - Low educational attainment
  - Higher rates of psychiatric morbidities
  - Traumatic brain injuries

- Risk of dementia in prisoners
  - In the USA estimated to be from 1% to 44%
  - In the UK estimated to be from 2% to 18%

- BUT REMAINS LARGELY UNKNOWN
But...

- Historical abuse of prisoners by medical research
  - Since the 19th Century until 1970s
    - Roberts and Indermaur 2008

- Cesare Lombroso
  - Father of criminology
Prisoners

Concerns of involving prisoners in research:

- Prisoners are a vulnerable research population due to:
  - constraints on their liberty and autonomy
  - coercive nature of the prison environment and regime
    - Lemer (2007), Christopher et al. (2011)

- Pragmatic concerns regarding perceived burden of including prisoners, rather than:
  - ethical concerns
  - knowledge of regulations
    - Charles et al. (2016)
Therefore...

- Prisoners to have ‘limited access’ to participate in research
- Ethics committees to be ‘insufficiently informed’ on issues of healthcare research in prisons
  - UREC
  - HRA
  - NRES
  - NOMS/Her Majesty's Prison and Probation Service - HMPPS
- Support of individual Governors
Research at HMPPS

We carry out and commission research to measure the effectiveness of offender management services, in the short or long term.

Contents
  — Research publications
  — Research contracts
  — Research application process
Current ethical guidance

- Committees apply the term ‘beneficial research’
- Prisoner’s should receive the same opportunity to participate in health research as other members of the population of the country they are detained
  - (Charles and Draper 2012).

However

- NRES guidance and decisions is more restrictive as only support research involving prisoners that can only be conducted within a prison population, which prevents research that isn’t exclusive to the prisoners or the prison setting
  - (Charles et al. 2016).
My experience

- **Ethics**
  - Observational study
  - Support of the Governor influential for NOMS

- **Research within the prison setting**
  - Increased time locked in cell when involving staff
  - Impact on delivery of health services

- **Educational delivery within the prison setting**
  - Registered professional in a controlled environment
  - Working with the prison regime
Prison environment

Challenges of the prison environment

- Confidentiality and privacy cannot be assured, due to:
  - the closed nature,
  - controlled nature
  - public nature of physical movement
  - accompaniment of prisoners to appointments
    - Gostin et al. (2006)
Four Pillars of Ethics

- **Autonomy**
  - BUT – power imbalance
  - BUT – obtaining informed voluntary consent
  - Need to assess capacity to consent
  - Difficult maintaining anonymity and confidentiality

- **Beneficence**
  - The duty to do good – impact on the prison regime

- **Non-maleficence**
  - The duty to not do bad – impact on the prison regime

- **Justice**

Beauchamp and Childress (2001)
Four main principles

- **Respect for the client’s rights and dignity**
  - Understanding the implications and context in which the research is taking place

- **Competence**
  - Knowledge of the prison setting and specific ethical issues related to health research in prison

- **Responsibility**
  - Avoid harm and act in the prisoners best interests and be responsible for our actions

- **Integrity**
  - Act honestly, impartially, and respectfully
    - Dalen et al. (2010)
How to proceed

- Unbiased risk benefit analysis

- Prisoners are equally and equitably involved in research to ensure justice

- Prison setting is equally and equitably involved in research to ensure justice

- Development of an ethical framework and guidance to address all of the issues discussed
Thank you

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