

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)
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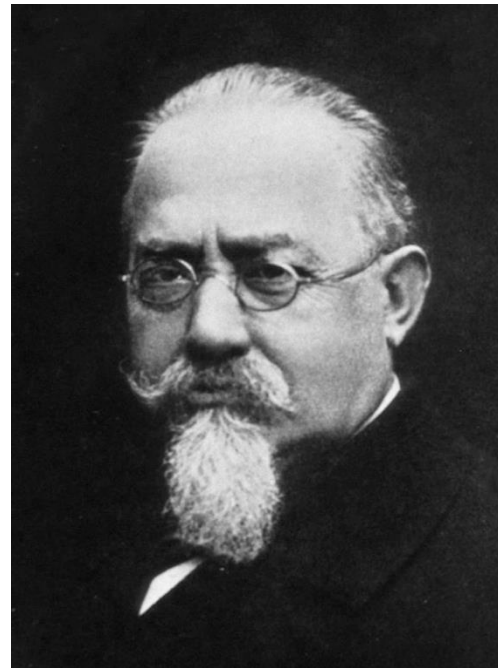
Dementia in Prison

- ▶ 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



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Her Majesty's Prison & Probation Service

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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