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Patient Wellbeing in Forensic Mental  
Health

A systematic review of internalised stigma and an empirical  
qualitative study of the wellbeing of older people in secure  
forensic mental health wards in Scotland

**Jane-Louise Jackson**

Doctorate in Clinical Psychology (D.Clin.Psychol)

University of Edinburgh

2018

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## DClinPsychol Declaration of Own Work

**Name:** Jane-Louise Jackson

**Title of Work:** Patient Wellbeing in Forensic Mental Health. A systematic review of internalised stigma and an empirical qualitative study of the wellbeing of older people in secure forensic mental health wards in Scotland

*I confirm that this work is my own except where indicated, and that I have:*

- Read and understood the Plagiarism Rules and Regulations
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  - Clearly referenced/listed all sources as appropriate
  - Referenced and put in inverted commas any quoted text of more than three words (from books, web, etc.)
  - Given the sources of all pictures, data etc. that are not my own
  - Not made undue use of essay(s) of any other student(s), either past or present (or where used, this has been referenced appropriately)
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  - Acknowledged in appropriate places any help that I have received from others (e.g. fellow students, technicians, statisticians, external sources)
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  - Received ethical approval from the School of Health in Social Science, University of Edinburgh
- OR
- Received ethical approval from an approved external body and registered this application and confirmation of approval with the School of Health in Social Science's Ethical Committee

**Signature**



**Date** 31<sup>st</sup> July 2018

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## List of Abbreviations

ASPD- Anti-social Personality Disorder

BACS- Beliefs About Criminals Scale

CJS- Criminal Justice System

CRD- Centre for Research and Dissemination

DSM- Diagnostic and Statistical Manual of the Mental Disorders

EDS- Experience of Discrimination Scale

ES- Effect Size

GTM- Grounded Theory Methodology

ICD- International Classification of Diseases and Related Health Problems

IPES- Inmates Perceptions and Expectations of Stigma

ISMIS- Internalised Stigma of Mental Illness Scale

MH- Mental Health

NCR-MD - Not Criminally Responsible on account of Mental Disorder

NICE- National Institute for Health and Care Excellence

PD- Personality Disorder

RMO- Responsible Medical Officer

SIGN- Scottish Intercollegiate Guidelines Network

SS- Stigma Scale

SSICR- Self-Stigma of Individuals with Criminal Records

SSMIS- Self-Stigma of Mental Illness Scale

TST- Twenty Statements Test

## Word Counts

Thesis- 20,656 words

Chapter 1- Systematic review: 9,881 words

Chapter 2- Empirical paper: 10,775 words

# Full Thesis Abstract

## ***Background***

The world's population is ageing and the proportion of older people in forensic mental health settings is growing. Stereotypical views of ageing and older people can be negative and lead to discrimination. Forensic mental health patients experience multiple stigmas which may impact on wellbeing. A better understanding of wellbeing and stigma in forensic mental health is needed.

## ***Aims***

The first chapter in this thesis aimed to systematically review literature to identify the consequences and correlates of internalised stigma in forensic mental health. The second chapter describes a qualitative exploration of the wellbeing of older people in forensic mental health inpatient settings, from the perspective of patients (older than 55 years) and staff.

## ***Methods***

In chapter one, nine bibliographic databases were systematically searched for forensic/criminal mental health studies reporting on a quantitative statistical relationship between a measure of internalised stigma and at least one other variable. 13 papers were quality assessed and the data was narratively synthesised. In chapter two, 10 inpatients (age 55+) from secure forensic mental health inpatient services were interviewed and 14 staff took part in focus groups about the wellbeing of older people in those settings. Using Grounded Theory Methodology, concurrent data collection and analysis led to the construction of a theoretical model of the wellbeing of older people in this setting.

## ***Results***

The systematic review of literature found that higher levels of internalised stigma were related to lower self-esteem, more severe symptoms of mental ill-health and having a prior history of homelessness and incarceration. Internalised stigma was found to be lower in those who had attended a peer support group, on average, compared to non-attendees. The empirical paper constructed a substantive theory of 'Becoming a better person' and the following core categories relevant to promoting wellbeing of older people: relationships, health, knowledge and skills, social context and interests.

## ***Conclusions***

No definitive conclusions can be drawn from the systematic review paper due to the heterogeneity of study designs, methods and measurement tools. However, findings were

in line with that of a 2010 review and recommendations regarding future research are made, including the need for a specific tool to measure internalised stigma in a forensic mental health population. The empirical paper concluded that the older people wanted to re-engage with their sense of self and past skills and interests, as well as developing new skills. A values-based approach to wellbeing in older people was recommended to enhance wellbeing through values-consistent actions by staff and patients. The model itself was grounded in data which confirmed past literature around increasing health needs with age.

## Lay Thesis Summary

Public attitudes towards those with mental ill-health and/or criminal offending backgrounds tend to be negative and can lead to stigma and discrimination. This impacts on the individuals and the public as psychological responses to stigma have been seen to actually increase risk of re-offending. Another stigmatised population is older people and due to the world's ageing population the forensic mental health system has more older patients than ever before. Therefore, wellbeing of older people in these services is becoming more important, although past research is limited. This thesis investigates factors that impact on the wellbeing of older people (defined as age 55+ in this population) whose difficulties are supported by forensic services.

The research is split into two parts, the first defines forensic services as those which involve people either with criminal or offending backgrounds, or who are detained by the criminal justice or mental health system due to their risk to others. These places include hospitals, secure units, prisons, community rehabilitation and health services. The second involves people only in secure forensic mental health wards and hospitals in Scotland.

The first chapter reviewed the results of past research studies on the effect of internalised stigma on people in forensic settings with mental ill-health. Internalised stigma is when someone agrees with negative stereotypes about a part of themselves (like their mental health) and believes it about themselves. It can develop from people's experiences of discrimination, which happens in this population due to the stigma of mental illness and of being a criminal. Reviewed studies showed that internalised stigma is related to lower self-esteem, more severe symptoms of mental illness, not taking medication as advised and having a background of being homeless or in prison. Another study found being part of a

peer support group was related to a reduction in internalised stigma. The reviewed studies compared internalised stigma to different factors, both of which were measured using a variety of different tools. Due to the variety of techniques used in previous studies it was concluded that more research is needed in this area to work out how best to measure stigma in a forensic mental health population. This would help future reviews compare and analyse more study results together, providing more meaningful information.

From this review, stigma was shown to have significant psychological consequences when internalised, which impacted on wellbeing. In addition, the relationship between more significant mental health problems and higher levels of stigma seemed relevant to consider with the older subset of forensic mental health patients, as they have typically experienced more severe and enduring mental illness.

The second chapter describes research which interviewed 10 male patients, age 55 years or older, about their wellbeing and 14 staff in secure forensic mental health wards about the wellbeing of older patients. The results showed that older patients needed appropriate housing, enough money, accessible services, positive relationships, interests, knowledge and skills to promote their wellbeing. Patient and staff accounts were used to construct a theoretical model of wellbeing. This model described a process of understanding, reflecting on what matters, accepting and adapting to context, thinking about the future and behaving according to what you value. The model could be used to help staff and patients understand what is involved in an older person's journey through forensic mental health services, including the factors that contribute to how these are experienced in terms of their wellbeing. More research is needed to compare between different hospitals and wards in case of local differences. It would also be beneficial to explore the wellbeing of women in similar situations to capture any specific needs.

In summary, this thesis set out to examine the consequences of internalised stigma in a forensic mental health population and explore the wellbeing of older people in this setting. Social context played a part in both studies, as stigma and discrimination was seen to impact on factors related to wellbeing. The results can be used to inform services regarding the impact of stigma and other factors on forensic mental health patients and particularly on the wellbeing of older people in these settings.

# Chapter 1- Correlates and Consequences of Internalised Stigma in forensic mental health: A systematic review of literature

## **Authors**

Ms Jane-Louise Jackson<sup>1,2</sup>, Ms Julie Riddell<sup>3</sup>, Dr Ethel Quayle<sup>2</sup>, Dr Clare Neil<sup>1</sup>

## **Affiliations**

<sup>1</sup>NHS Forth Valley, <sup>2</sup>University of Edinburgh, <sup>3</sup> MRC/CSO Social & Public Health Sciences Unit, University of Glasgow

## **Corresponding Author**

Jane-Louise Jackson, Westburn Building, Falkirk Community Hospital, Falkirk, FK1 5SU

This chapter is written according to 'The Journal of Forensic Psychiatry and Psychology' author guidelines for review articles (see Appendix A), with the exception of presentation format, which has been carried out according to the University of Edinburgh's 'Standards for the Formatting and Binding of a Thesis' for postgraduate research theses and the inclusion of tables/figures within the text for ease of reading.

## Abstract

### **Background**

Internalised stigma develops when individuals agree with and apply negative stereotypes about a group (of which they are a member) to themselves. Forensic mental health patients typically have multiple stigmatised identities.

### **Question**

What are the correlates and consequences of internalised stigma in forensic mental health?

### **Method**

This study searched nine bibliographic databases for relevant published and grey literature in forensic mental health. Studies had to include a measure of internalised stigma and at least one other variable and report on the statistical relationship between them.

### **Results**

13 papers were included in a narrative synthesis. Internalised stigma was negatively correlated with self-esteem, wellbeing, medication adherence, participation in a peer support group and therapeutic alliance, and positively correlated with severity of mental health symptoms, and prior history of homelessness or incarceration.

### **Conclusion**

Findings reflect those of a similar systematic review with a non-forensic population. Overall levels of internalised stigma were lower than expected. The variety of tools used to measure internalised stigma and the heterogeneity of study designs, sample characteristics and settings meant that no definitive conclusions could be drawn. Internalised stigma of mental ill-health and criminality should be considered together in future studies, rather than being seen as operating individually.

**Keywords:** *Forensic, Mental Health, Stigma, Systematic Review, Internalised Stigma*

## 1.1 Introduction

Stigma is a process where negative beliefs about individual or group characteristics are socially constructed as stereotypes, resulting in the judgement and discrimination of those possessing those characteristics (Livingston & Boyd, 2010). Past stigma research explored areas including mental health, HIV/AIDS, race and sexuality, however stigma can relate to anything about an individual or group that can be distinguished and labelled as outside the 'norm' (Pescosolido & Martin, 2015). This paper aims to explore stigma in a population that hold at least two such stigmatised identities, those with mental ill-health and criminal offending histories.

Operating in interpersonal relationships, communities and public services (Bos, Pryor, Reeder, & Stutterheim, 2013; Link & Phelan, 2001), stigma has been conceptualised on three levels: public, structural and internalised (Pescosolido & Martin, 2015). Public stigma describes the process whereby prejudiced attitudes lead to implicit or explicit behavioural responses, including avoidance behaviours to create social distance from the stigmatised individual or group (Corrigan, Rafacz, & Rüscher, 2011). Public stigma is prevalent in offending and mental health populations, with negative public attitudes based on stereotypes around dangerousness, anti-sociality and unpredictability (Maclin & Herrera, 2006; Rade, Desmarais, & Mitchell, 2016). Criminal justice staff were found to share these attitudes, however mental healthcare staff held significantly less stigmatising attitudes than the general public. Nonetheless, staff and public in both settings desired social distance (Wang, Link, Corrigan, Davidson, & Flanagan, 2018; Yuan et al., 2017), particularly in response to the most stigmatised individuals within these groups (sexual offenders and those with severe and enduring mental health problems including schizophrenia, personality disorders or longstanding bipolar affective disorder) (Clemente, Santos, Nicolato, & Firmo, 2017; Hill & Startup, 2012; Kelly, 2005; Rade et al., 2016; Stuber, Rocha, Christian, & Link, 2014). In contrast, a study of offenders post-release found no significant difference in the perceptions and experiences of stigma between 'extensive' and 'minor' offences (Ispalanda & Loeffler, 2016). These findings suggest implications for interventions targeting stigma-reduction, as the behavioural response of staff shows that work is still needed to address their attitudes regarding the people they support. However, inconsistent findings regarding the association between stigma and population sub-groups (e.g. types of offence) make it difficult to target psychoeducational materials about the most stigmatised

individuals. Anti-discrimination campaigns and equality of care provision for mental and physical health have come some way to challenging public attitudes and structural stigma regarding mental health. However, in most countries, mental health services continue to receive a relatively lower proportion of funding compared with physical health services (Rossler, 2010). Furthermore, as stigma informs the societal values that shape how mental health is interpreted (e.g. as a manifestation of a person's own weaknesses), it impacts on the societal power of those with mental ill-health and limits public awareness and investment in vital services (Moore, Tangney, & Stuewig, 2016; Sheehan, Nieweglowski, & Corrigan, 2017).

When individuals are aware that they hold a stigmatised identity, they are likely to anticipate stigma and discrimination from others. This has been associated with the concealment of the stigmatised characteristic, or by the individual choosing to manage their problems alone to avoid being subject to labelling and discrimination (Jennings et al., 2015; Kulesza, Pedersen, Corrigan, & Marshall, 2015; Rendina, Millar, & Parsons, 2018; Sharp et al., 2015). The 2017-2027 Mental Health Strategy recognises a reluctance to seek help (as a result of mental-health stigma) as a barrier to services (Jennings et al., 2015; Kulesza et al., 2015; Scottish Government, 2017; Sharp et al., 2015). In this way, stigma operates on a structural level by limiting an individual's access to support and resources (Hatzenbuehler, 2016; Sheehan et al., 2017), which further contributes to the disadvantages people with mental ill-health have in society (Boardman, 2011). Structural stigma has been conceptualised as a process of discrimination where stigmatised individuals or groups are intentionally or unintentionally excluded from services or have their options restricted by policies or systems (Corrigan, 2004; Pescosolido & Martin, 2015). People with criminal records are often socially and structurally marginalised according to restrictions placed on them following their charge or sentence. These vary with local and national laws, but can include having limitations on travel, community participation, voting rights and employment (Ahmed & Lång, 2017; Decker, Ortiz, Spohn, & Hedberg, 2015; Ispalanda & Loeffler, 2016; Moore, Stuewig, & Tangney, 2016). Such restrictions are in place to protect the public, however these have negative consequences for the offenders themselves. For example, the community notification policy, named 'Megan's Law' was introduced in some States of America to assist in public protection from people convicted of sexual offences. Some studies have reported negative psychosocial consequences for the

sexual offenders themselves, such as isolation, psychological distress and shame, in addition to the imposed practical barriers to housing and financial aid (Lasher & Stinson, 2017; Levenson, Amora, & Hern, 2007). Moreover, the Protection of Vulnerable Groups scheme (PVG) in Scotland means that job applicants' charges are disclosed prior to them commencing work so that employers can make informed hiring decisions about the relevance of their charges and potential risk (Scottish Government, 2011). Guidance has been issued to help employers apply the PVG scheme fairly, such that it is not used to discriminate against offenders, however research continues to find evidence of perceived stigma and discrimination when offenders apply for work post-release (Ahmed & Lång, 2017; Scottish Government, 2015). As the success of offender community reintegration is typically measured in terms of recidivism, it seems reasonable to suggest that people with offending histories should be supported to integrate with and contribute to society, as without a reasonable quality of life and wellbeing, risk of recidivism is known to rise (Alliance Group, 2017; Grossi, 2017).

Managing risk of recidivism is also relevant to forensic mental health services, where staff work to balance public protection with mental healthcare. The forensic mental health population have significant rates of often severe and enduring mental-health problems and other complex difficulties, making them a particularly vulnerable group in society (Forensic Network, 2011). Patients in forensic mental health settings are likely to experience stigma and discrimination according to their membership of multiple stigmatised groups (e.g. mentally ill, offender), the consequences of which may be two fold (Gausel & Thørrisen, 2013; LeBel, 2012; West, Yanos, & Mulay, 2014). Structurally, people may be excluded from services due to perceived or actual co-morbid substance misuse, cognitive impairment or behavioural problems (Pinals, 2014). In addition, how services operate may result in the unintentional exclusion of individuals from mental healthcare. A recent audit of rejected referrals to Child and Adolescent Mental Health Services (CAMHS), raised an issue with referral criteria, such that those in need may be rejected if they are not reported to have a significant 'mental illness' on the referral document (Wray, 2018). This is a shared concern in other mental health services, including forensic as it may lead to individuals missing out on the care and support they need to manage their mental health and, in turn, manage risk. The forensic mental health population may also find it difficult to attend community appointments due to financial or logistical problems and lack of social/family support. This

can exclude people from services all together, or cause them to be discharged prematurely due to services' attendance policies (Feitsma, Popping, & Jansen, 2012; Mitchell & Selmes, 2007). These issues add to and exacerbate negative stereotypes about this group (and their families and friends) leading to a vicious cycle involving stigma, reduced help-seeking, non-attendance, exclusion, higher financial cost to services, strict access and attendance policies, unsupported mental health problems and increased risk of recidivism (Corrigan, 2004; Fox, Smith, & Vogt, 2016; Stoel, Houtepen, Van Der Lem, Bogaerts, & Sijtsema, 2018).

As well as the impact of structural stigma, perceiving or having experienced stigma has been linked with poorer health outcomes, stress, disempowerment and low self-esteem when mediated by internalised stigma (Link & Hatzenbuehler, 2016; Rendina et al., 2018; Thille, Friedman, & Setchell, 2017; Wang et al., 2018). Another study, however found that self-efficacy mediated the relationship between perceived and internalised stigma (Hill & Startup, 2012) and other moderating factors such as race further complicated this process (Moore, Tangney, et al., 2016; West, 2015). Regardless, consensus between models of internalised stigma see stereotypical beliefs about a group of people internalised when an individual perceives and then agrees with the stereotypes and applies them to their sense of self (Drapalski et al., 2013; Moore, 2016; Moore, Tangney, et al., 2016). This conceptualisation of internalised stigma is consistent with many of the studies reviewed in a 2010 meta-analysis in this area (Livingston & Boyd, 2010). This paper investigated the consequences and correlates of internalised stigma of mental illness and concluded that it was positively associated with psychiatric symptom severity and negatively associated with self-esteem, treatment adherence, hope and empowerment (Livingston & Boyd, 2010). Following this review, more evidence was found to support the negative correlational relationship between internalised stigma and self-esteem and psychiatric symptom severity (Drapalski et al., 2013; Link & Hatzenbuehler, 2016; Thille et al., 2017; Wang et al., 2018). In addition, a review of internalised stigma measurement tools extended Livingston and Boyd's (2010) model of internalised stigma to encompass stereotype endorsement rather than seeing it as a preceding factor (Stevenson, Wu, Voorend, & van Brakel, 2012). This is another example of how conceptualisations of internalised stigma vary between papers and gives reason to the need for more empirical studies exploring contributing and correlating variables.

Although there has been increased interest in internalised stigma of mental illness and how it is measured, there has been less focus on the study of multiple stigmatised identities, such as those of people involved with forensic mental health services. What is clear from the literature is that stigma is detrimental for the mental health of individuals with offending histories and that is likely to impact on society through the relationship between mental health and risk of recidivism (West et al., 2014). A better understanding of internalised stigma in this group is needed, so that policies can be made more inclusive and services and interventions are more accessible and appropriate for the needs of those most impacted by stigma (Hatzenbuehler, 2016; Link & Hatzenbuehler, 2016). This present review study aims to build on Livingston and Boyd's (2010) review by identifying the consequences and correlates of internalised stigma in forensic mental-health contexts. This will further the current understanding of mental health stigma provided by Livingston and Boyd (2010) by considering an added forensic identity. To the researcher's knowledge, no other systematic review has been undertaken with this specific population and it is hoped that the results of this review will encourage others to consider what needs to be done to reduce stigma in this context.

## 1.2 Method

### **1.2.1 Search Method**

Prior to conducting this systematic review, the Centre for Research and Dissemination (CRD) and the International Prospective Register of Systematic Reviews (PROSPERO) were searched in order to discover any past or in-progress reviews of a similar nature to the present study. No such reviews were found and the intended protocol was registered with PROSPERO and published online in May 2018 (see Appendix B). Following initial scoping searches, nine bibliographic databases were searched for relevant published and grey literature from their date of inception until 12<sup>th</sup> April, 2018. Search terms were devised using those from similar reviews and adding terms from relevant papers found during the scoping searches. Advice was sought regarding search terms, syntax, database selection and use of interfaces from the University of Edinburgh's School of Health in Social Science Academic Librarian. Table 1.1 gives details of the search syntax used for each interface and the databases included within these.

Table 1.1: Summary of search syntax and databases searched

Interface	Databases Searched	Search terms and syntax
<b>Ovid</b>	<ul style="list-style-type: none"> <li>- PsychINFO</li> <li>- Embase</li> <li>- Ovid MEDLINE (R) In-Process &amp; Other Non-Indexed Citations</li> <li>- Ovid MEDLINE (R)</li> <li>- Ovid MEDLINE (R) Epub Ahead of Print</li> <li>- Ovid MEDLINE (R) Daily (1956- date of search)</li> </ul>	"stigma*" OR "discriminat*" OR "marginali*" OR "alienati*" <b>AND</b> "mental health" OR "mental disease" OR "mental ill*" OR "mental* ill" OR "mental* disordered" OR "mental disorder" OR "schizophren*" OR "psychos*" OR "psychot*" <b>AND</b> "prison*" OR "offend*" OR "forensic*" OR "criminal*" OR "correction*" OR "secure hospital*" OR "secure ward*" OR "secure unit*"
<b>ProQuest</b>	<ul style="list-style-type: none"> <li>- International Bibliography of the Social Sciences (IBSS)</li> <li>- Applied Social Sciences Index and Abstracts (ASSIA)</li> <li>- Social Services Abstracts</li> <li>- PAIS International</li> <li>- Criminal Justice</li> <li>- ProQuest Dissertations &amp; Theses Global</li> </ul>	"stigma*" OR "discriminat*" OR "marginali*" OR "alienati*" <b>AND</b> "mental health" OR "mental disease" OR "mental ill*" OR "mental* ill" OR "mental* disordered" OR "mental disorder" OR "schizophren*" OR "psychos*" OR "psychot*" <b>AND</b> "prison*" OR "offend*" OR "forensic*" OR "criminal*" OR "correction*" OR "secure hospital*" OR "secure ward*" OR "secure unit*"
<b>EBSCOhost</b>	<ul style="list-style-type: none"> <li>- CINAHL</li> </ul>	"stigma*" OR "discriminat*" OR "marginali*" OR "alienati*" <b>AND</b> "mental health" OR "mental disease" OR "mental ill*" OR "mental* ill" OR "mental* disordered" OR "mental disorder" OR "schizophren*" OR "psychos*" OR "psychot*" <b>AND</b> "prison*" OR "offend*" OR "forensic*" OR "criminal*" OR "correction*" OR "secure hospital*" OR "secure ward*" OR "secure unit*"

Additional searches were carried out by consulting the reference lists of included full-text papers, additional relevant papers, and conference proceedings.

### 1.2.2 Selection Criteria

At each stage of this review, papers were assessed for their relevance to the review question using the criteria as stated in table 1.2. The following information was obtained regarding papers which were excluded following full-text review: Author, Year of Publication, Title and reason for exclusion (see Appendix C).

For the purposes of this review, the definition of 'mental ill-health' used is that provided by the individual paper. This is likely to include people deemed as having diagnosable conditions noted in the Diagnostic and Statistical Manual of the Mental Disorders- 5<sup>th</sup> Edition (DSM-V), International Classification of Diseases and Related Health Problems- 10<sup>th</sup> Edition (ICD-10) or NHS Scotland's Psychological Therapies Matrix. This definition can also include those labelled as forensic psychiatric/mental health patients, people with measured or reported mental health symptoms or mental health which is deemed clinically relevant by the individual paper's author(s). For this review, the term 'forensic' may be used to

describe the population or setting, with forensic services including prisons, forensic mental health services (inpatient and outpatient/community), criminal justice and correctional facilities.

*Table 1.2: Criteria for papers to be included or excluded in systematic review*

<b>Inclusion Criteria</b>	<b>Exclusion Criteria</b>
Quantitative research designs Including measure(s) pertaining to self/internalised stigma	Qualitative research or descriptive papers Editorials and Commentaries
Assessing and reporting on statistical relationship between self/internalised stigma and at least one other variable	Conference proceedings where full-text is not available
Population: - Adults age 18+ years - Contact with forensic services - Mental ill-health	Population: - People under 18 years old - Non-forensic population - No mental ill-health - Sole diagnosis of Dementia, Learning Disability, cognitive impairment, brain injury or substance misuse disorder
Full-text in English retrievable via University of Edinburgh, NHS Scotland and local library subscriptions, corresponding author or unpaid translation	Non-English language papers where translation is not feasible
Primary research question	Review papers

Finally, the definition of internalised stigma used in the current review is based upon that of Livingston and Boyd (2010):

‘...internalised stigma as a subjective process, embedded within a socio-cultural context which may be characterised by negative feelings (about self), maladaptive behaviour, identity transformation, or stereotype endorsement resulting from an individual’s experiences, perceptions or anticipation of negative social reactions...’ (Livingston & Boyd, 2010, p. 2151).

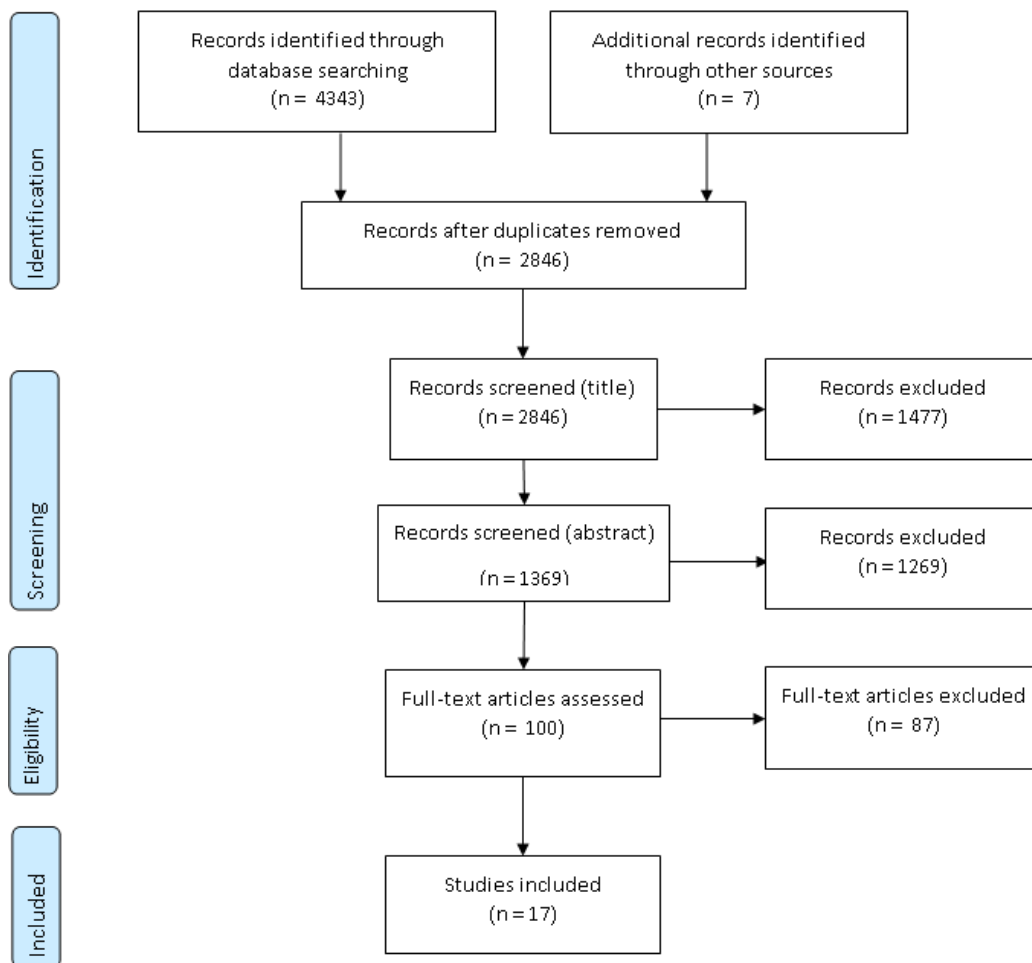
As per Livingston and Boyd (2010), this paper will use the term ‘internalised stigma’ to describe internalised/self-stigma, defined as above and developed on the basis of mental ill-health and/or forensic experiences.

### 1.2.3 Selection Process

The titles of papers found via database and additional searching were screened and papers that were clearly irrelevant to the review question and did not meet the inclusion criteria were excluded at this stage. Abstracts of remaining studies were then screened according to inclusion criteria. Following this, English-language full-texts were sought for the remaining studies and read in full to assess their suitability for inclusion.

A diagrammatic representation of the screening and review process is shown in Figure 1.1. This is presented using the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) diagram and gives the numbers of papers retrieved and excluded at each stage of the screening and review process (Moher, Liberati, Tetzlaff, & Altman, 2009).

Figure 1.1: PRISMA Diagram showing literature search process



Corresponding authors were contacted to request the full-text of articles which were unavailable to the first author via the University of Edinburgh, NHS Scotland or local library subscription services. Corresponding authors were also contacted for English-language translations, should the paper have been published in another language. There was no budget or availability of translation services for this study, so for the most part, only English-language papers were included. However, where possible the first author sought unpaid translations via contacts obtained through the University of Edinburgh's Masters programme in Translation Studies. This enabled the inclusion of one paper written and published in French in the final review.

In order to reduce the likelihood of human error, co-reviewing was carried out by the second author (JR). 10% of the abstracts were co-screened (Cohen's kappa=0.62) and 50% of the full-texts were co-reviewed for inclusion in the final review (Cohen's kappa=0.45). Discrepancies were resolved by discussion until a consensus was reached.

#### ***1.2.4 Data Extraction and Quality Assessment***

Characteristics, measurement tools and key findings were sourced and extracted from the included 13 papers by the first author, with 30% checked for accuracy by the second author. Where standardised measures of internalised stigma were used, original papers were sourced in order to gain information on their development and psychometric properties (see section 1.3.1).

A past systematic review of similar studies was examined and found not to include an assessment of quality (Livingston & Boyd, 2010). A review of systematic reviews and meta-analyses in health research highlighted this issue as only 51% of papers reviewed assessed risk of bias (Oliveras, Losilla, & Vives, 2017). However, the Scottish Intercollegiate Guidelines Network (SIGN) recommend that study methodologies should be subject to a quality assessment where studies are potential sources of evidence for health care and/or interventions (Scottish Intercollegiate Guidelines Network, 2015). Agreement is broadly noted between SIGN and other bodies that quality and risk of bias assessments should be performed and that there are particular types of factors which should be assessed. These include those factors likely to contribute to an increased risk of selection, performance, detection, attrition and reporting biases (Higgins & Green, 2011). Examining the

appropriateness of the study design, choice of outcome measure(s), statistical (or other) analyses, quality of intervention (if applicable), the quality of the reporting and generalisability of the findings is recommended (Centre for Research and Dissemination, 2009; National Institute for Health and Care Excellence, 2012; Scottish Intercollegiate Guidelines Network, 2015). In order to cover these areas, some review papers use assessment tools, however these are varied and studies apply them inconsistently (Seehra, Pandis, Koletsi, & Fleming, 2016).

Due to the present review including studies of differing designs, the first author developed a quality assessment tool with criteria based upon relevant questions from the National Institute for Care Excellence's (NICE) checklists for intervention and correlation/association studies (National Institute for Health and Care Excellence, 2012) as well as Centre for Research and Dissemination (CRD) and SIGN recommendations (Centre for Research and Dissemination, 2009; Scottish Intercollegiate Guidelines Network, 2015). This customised tool (see Appendix D) includes questions to ascertain detail about the aforementioned factors, such that a thorough quality assessment may be performed. This tool was piloted initially on three papers then adjusted to enable all relevant data to be extracted from the 13 included papers, such that a quality assessment could then be undertaken.

## 1.3 Results

### ***1.3.1 Characteristics of Included Studies***

Details and key findings, relevant to the review question, can be found in table 1.3 for each of the included papers. Papers were published (or dated, in the case of theses) between 2008 and 2018. Of the 13 included papers, five reported intervention studies (two papers from one RCT) and the remainder were cohort studies. Studies were carried out in the USA (71.4%), Canada (14.2%), France (7.1%) and the UK (7.1%) and all but one (Dequelson, Saloppe, & Bandinelli, 2015) were published in English. Recruitment settings included forensic mental health or criminal justice community (n=4) and inpatient services or caseloads (n=5), medium security correctional facilities and detention centres (n=5), mental health court diversion programmes (n=2) and prison (n=1).

Sample sizes involved in stigma analyses ranged from 10 (Vogel, 2015) to 16000 (Ali, Teich, & Mutter, 2018) and included people aged 18 to 69 years old. Studies included people from

a range of ethnic backgrounds, apart from one which studied solely individuals self-identifying as Latino (Eno Louden & Manchak, 2018). Seven papers sampled a mix of female and male participants, ranging from a proportion of 20% to 40% female compared to male. Three papers presented studies of only females (Bentley & Casey, 2017; Dequelson et al., 2015; Long, Fulton, & Dolley, 2015) and three of only males (Moore, Milam, Folk, & Tangney, 2017; Moore, Tangney, et al., 2016; Vogel, 2015). Individuals were noted as having mental health problems through their participation in an intervention for mental health or engagement with a mental health service. Diagnoses were noted in sample characteristics for eight studies and included schizophrenia, schizoaffective disorder, bipolar affective disorder, other psychotic disorder, anxiety, depression and personality disorder. Diagnoses were mostly obtained through self-report. Remaining studies defined participants as having 'serious' or 'severe' mental health problems.

How internalised stigma was conceptualised and measured across the included papers varied. Eight papers measured the internalised stigma of mental-illness, two measured that of criminality/offending and three measured both. In terms of tools, the papers used a variety of instruments which, where reported, had 'good' to 'excellent;' psychometric properties ( $\alpha$ = internal consistency,  $r$ = test/retest reliability) in terms of the subscales or questions pertaining to internalised stigma. These were: Internalised Stigma of Mental Illness scale (ISMIS) ( $\alpha$ =0.9,  $r$ =0.92, good concurrent and divergent validity) (Ritsher, Otilingam, & Grajales, 2003) ( $n$ =6); Self-stigma of Individuals with Criminal Records (SSICR) ( $\alpha$ =0.73) (Moore, Tangney, et al., 2016) ( $n$ =2), Self-stigma of Mental Illness scale (SSMIS) ( $\alpha$ =0.72-0.91) (Corrigan, Watson, & Barr, 2006) ( $n$ =1); the disclosure subscale of the Stigma Scale (SS) ( $\alpha$ =0.85) (King et al., 2007) ( $n$ =1); Experience of Discrimination Scale (EDS) (V. L. S. Thompson, Noel, & Campbell, 2004) ( $n$ =1); Inmate Perceptions and Expectations of Stigma (IPES) ( $\alpha$ =0.81-0.83) (Mashek, Meyer, McGrath, Stuewig, & Tangney, 2002) ( $n$ =1); and Twenty Statements Test (TST) (Kuhn & McPartland, 1954) ( $n$ =1). Three papers developed questionnaires or checklists which pertained to internalised stigma by asking about secrecy, embarrassment or shame regarding their mental health (MH) or offending status (Ali et al., 2018; Bentley & Casey, 2017; Reinsmith-Meyer, 2008). Another paper developed a new subscale of the Beliefs about Criminals Scale (BACS) (Mashek et al., 2002), to measure self-concept regarding having a criminal background: 'BACS-C' (West, Vayshenker, Rotter, & Yanos, 2015). This subscale used items similar to the original BACS subscales ( $\alpha$ =0.81-0.83).

Analyses compared measures of internalised stigma with a number of different variables, including socio-demographic (e.g. age, gender, race, length and number of incarceration(s)/admission(s)), mental health (e.g. symptom severity, number of diagnoses, positive and negative symptoms), personal (e.g. self-esteem, personality and knowledge of personality disorders, quality of life), treatment (e.g. engagement and level of participation, working alliance and adherence) and within-measure stigma subtypes (e.g. anticipated, experienced and perceived stigma, attitudes towards others and stereotype agreement).

Table 1.3: Summary of Included Studies

Study Description	Design	Sample	Demographics and Mental Health	Stigma Measure	Other measure(s)	Intervention	Relevant Findings
(Ali et al., 2018) USA	Cohort  NSDUH Study	N =16000 (CJS with unmet mental health (MH) need)  N=58000 (non-CJS with unmet MH need)	Mean age= 36  60% Male 40% female  62% non-Hispanic White 18% non-Hispanic Black 15% Hispanic 1% non-Hispanic Asian 4% non-Hispanic other	Why not receiving treatment? 1) neighbours would have a negative opinion 2) did not want others to know 3) negative effect on his job 4) confidentiality	Perceived MH treatment need  Reason(s) for not getting MH treatment	-	CJS more likely to report perceived unmet MH treatment need (OR = 1.20, p <0.001)  CJS MH treatment higher relative risk of identifying stigma as the reason for unmet need (RRR = 1.99, p <0.001). Similarly for those with no MH treatment (RRR=1.68, p<0.001).
(Bentley & Casey, 2017) USA	Cohort	N=274  MH inpatients of medium secure correctional facility	37% age 25-34  100% Female  80% White 15% African-American 2% Multi-racial 2% Native American 1% Hispanic 1% Asian/Pacific island	35-item questionnaire (22 items re. beliefs and experiences of psychotropic medication plus 6 items from Rotter's internal-external control scale <sup>1</sup> )	Demographics: length of incarceration, number of incarcerations, current medication use and number of psychiatric diagnoses	-	Stigma experience predicted by length of incarceration (B=0.22, p=0.004) and external locus of control (B=0.35, p<0.05), but not age, race, number of incarcerations, current medication use or number of psychiatric diagnoses

(Dequelson et al., 2015) France	Cohort	N=21  Forensic hospital patients with schizophrenia	Mean age = 36.55±8.81	ISMIS <sup>2</sup>	Positive and negative syndrome scale (PANSS) <sup>3</sup>  Scale to assess unawareness of mental disorder (SUMD) <sup>4</sup>  Rosenberg self-esteem scale (RSES) <sup>5</sup>  Calgary depression scale for schizophrenia (CDSS) <sup>6</sup>  The drug attitude inventory (DAI) <sup>7</sup>	-	Significant positive correlation between CDSS and ISMIS discrimination ( $r=0.49$ , $p<0.05$ ) and alienation subscales ( $r=0.45$ , $p<0.05$ )  Significant negative correlation between current SUMD and ISMIS alienation ( $r=-0.52$ , $p<0.05$ )  Significant negative correlation between adherence and ISMIS stigma resistance subscale ( $r=-0.46$ , $p<0.05$ )  SUMD positively correlated with CDSS, but not when internalised stigma effect is controlled for.  No significant correlations between SSMIS and RSES scores.
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(Eno Louden & Manchak, 2018) USA	Cohort	N=86	Mean age=34.2±11.3	ISMIS <sup>2</sup>	Treatment adherence: no missed appointments and missed appointments groups	-	No significant differences in ISMIS scores on any subscales between the adherence group
		Individuals on specialist MH caseload-serious MH disorder and having MH treatment as condition of probation	64% Male, 36% Female		Severity of symptoms (CSI) <sup>8</sup>		ISMIS (Alienation) M(nomiss)=13.24±5.07, M(miss)=13.71±4.15: p=0.65
			100% Latino/a (self-identifying as Latino/a, Hispanic, Mexican or Mexican-American)		Attitudes towards treatment (ATSPPH-S) <sup>9</sup>		ISMIS (Stereotype) M(nomiss)=13.25±4.01, M(miss)=14.06±4.19: p=0.37
					Acculturation (ARSMA-II) <sup>10</sup>		ISMIS (Discrimination) M(nomiss)=10.47±3.88, M(miss)=11.70±3.94: p=0.15
							ISMIS (social withdrawal) M(nomiss)=12.59±4.46, M(miss)=13.94±4.75: p=0.18

(Livingston, Rossiter, & Verdun-Jones, 2011) Canada	Cohort	N=91  <i>Forensic</i> N=52 (at T1) N=43 (at T2)  People previously found NCR-MD  <i>Civil</i> N=39  Included only if receiving compulsory community MH treatment for at least 30 days	Mean age=39±11.6 (range 21-65).  75.3% male 24.7% female  45% Caucasian 28% non-Caucasian  25% schizoaffective disorder 15.4% other psychotic disorder 1.9% bipolar	ISMIS <sup>2</sup> -removed stigma from total score -added 2 additional (separately analysed) forensic-specific items	Sociodemographic variables  Behaviour and Symptom Identification Scale (BASIS-24) <sup>11</sup>  Wisconsin Quality of Life Index (WQL) <sup>12</sup>  Canadian Community Health Survey (CCHS) <sup>13</sup>  Camberwell Assessment of Needs Forensic-Revised Edition (CANFOR) <sup>14</sup>	-	<i>Between-groups:</i> No significant difference in ISMIS between civil and forensic groups F=1.84, df=1.87, p=0.18 or any ISMIS subscales.  <i>Whole-sample:</i> Higher ISMIS scores associated with past incarceration, homelessness and current psychiatric symptom severity (28% of the variance).  Life satisfaction and wellbeing not significantly correlated with internalised stigma (5% of the variance).
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(Livingston, Nijdam-Jones, Lapsley, Calderwood, & Brink, 2013) Canada	Intervention	N=30 (baseline) N=25 (follow-up)  Measures completed by N=28 (baseline) N=22 (follow-up)  English speaking forensic MH inpatients, receiving MH treatment for at least 1 month	Mean age=42±10.78 (range=23-63)  80% Male 20% Female  88% White 12% Non-white  88% schizophrenia or other psychotic disorder 88% history of problematic substance use	ISMIS <sup>2</sup>	Mental health recovery measure (MHRM) <sup>15</sup>  Making Decisions Empowerment Scale (MDES) <sup>16</sup>  Singh O'Brien Level of Engagement Scale (SOLES) <sup>17</sup>  Level of participation (low, moderate or high)	19-month patient engagement intervention comprising 3 groups: peer support (76%), patient advisory committee (36%) and peer research team (32%)	No significant intervention effect on mean ISMIS scores between baseline and follow-up (T1)=2.07±0.42 (T2)=2.08±0.40 t(22)=-0.21, p>0.05  No significant impact of level of participation on the intervention effect internalised stigma between baseline and follow-up Low (n=8, Mdiff=-0.12±0.25) Mod (n=7, Mdiff=0.01±0.35) High (n=8, Mdiff=-0.09±0.21) F(2,22)=1.24, p>0.05  Pre-post mean differences in ISMIS scores significantly associated with participating in peer support (r=-0.43, p<0.05), but not with participation in the patient advisory committee (r=0.00, p>0.05) or peer research team (r=-0.25, p>0.05)
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(Long et al., 2015) UK	Intervention	N=36  Inpatients of 2 female medium secure inpatient wards admitted to the personality disorder treatment pathway over a two year period	Mean age = 23.4 ± 9.2 (range 18-45)  100% Female	SS- 10-item disclosure scale only used (SSD) <sup>18</sup>	Knowledge of personality disorder questionnaire (KPDQ)- developed for the present study <sup>19</sup>  Adult state hope scale (ASHS) <sup>20</sup>  Generalized self-efficacy scale (GSES) <sup>21</sup>  Short term assessment of risk and treatability (START) <sup>22</sup>  Inpatient/institutional behaviour scale (IIBS) <sup>23</sup>  Brief psychiatric rating scale- expanded version (BPRS-E) <sup>24</sup>	Understanding personality disorders group (psychoeducational intervention)  6x1hour sessions	Significant decrease in mean stigma disclosure between baseline Mean=34.5±8.3 and follow-up: Mean=25.2±5.2 for group-completers t(34)=3.93, p=0.01  Improvements were noted for a minority of non-completers on knowledge of personality disorder (21%) and stigma disclosure (28%).
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(Moore et al., 2017) USA	Intervention  Part of an RCT (Folk et al., 2015)	N=111  Male inmates of an adult detention centre (already sentenced and likely to spend it in host jail)	Mean age= 33±11 (range= 18-65)  100% Male  45.9% Black 34.2% White 11.7% Mixed/other race 4.5% Asian/Pacific islander 3.6% Hispanic	SSICR <sup>25</sup> adapted from the SSMIS <sup>26</sup>	Rosenberg self-esteem scale (RSES) <sup>5</sup>  Satisfaction with Life Scale (SWLS) <sup>27</sup>  Spiritual Transcendence Index (STI) <sup>28</sup>  Personality Assessment Inventory (PAI) <sup>29</sup> (MH/ASPD)  Texas Christian University Correctional: Residential Treatment Form, (substances) (TCU-CRTF) <sup>30</sup>  Inclusion of community in self- scale (ICS) <sup>31</sup>  Criminogenic Cognitions  Hare's Psychopathy Checklist (PCL:SV) <sup>33</sup>  Anti-social network of peers  Criminal identity	Restorative justice intervention (as detailed in Folk et al., 2015)	Internalised stigma was positively correlated with perceived stigma (r=0.28, p=0.003), stereotype agreement (r=0.48, p=0.00) and anticipated stigma (r=0.25, p=0.03)  Higher self-esteem at baseline predicted less internalised stigma at T2 (r=-0.25, p=0.008) Internalised stigma was positively correlated with mental health symptoms (r=0.41, p<0.001), Factor 2 psychopathy (r=0.27, p=0.005) and endorsement of ASPD features (r=0.38, p=0.001)  Higher levels of criminogenic cognitions predicted significantly more internalised stigma (r=0.22, p=0.002), particularly 'notions of entitlement' (r =0.20, p =0.04) and failure to accept responsibility (r=0.45, p=0.001)  No significant relationships were found between any stigma component and criminal identity, race, years of education, substance dependence, symptoms, spirituality, Factor 1 psychopathy, satisfaction with life and connectedness to the community at large
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(Moore, Tangney, et al., 2016) USA	Intervention Part of an RCT (Folk et al., 2015)	N=203 N=111 (stigma measures) Male sentenced inmates of an adult detention centre	Mean age= 33±11 (range= 18-65) 100% Male 43.8% Black 38.4% White 4.4% Hispanic 9.9% mixed/other race 2.5% Asian/Pacific islander 1% Middle Eastern	SSICR <sup>25</sup> adapted from the SSMIS <sup>28=6</sup>	Self- reported race Attitudes toward individuals with criminal record Criminal identity Rosenberg self-esteem scale (RSES) <sup>5</sup> Shortened version of the PAI <sup>29</sup> (depression/anxiety)	Restorative justice intervention (as detailed in Folk et al., 2015)	SSICR positively correlated with anxiety ( $r=0.21$ , $p<0.05$ ), depression ( $r=0.32$ , $p<0.01$ ) and negatively correlated with RSES ( $r=-0.22$ , $p<0.05$ ) SSICR not significantly correlated with treatment status, race, attitudes toward criminals or criminal identity  <i>Bivariate correlations:</i> significant positive correlations between internalised and anticipated stigma for black ( $r=0.34$ , $p=0.05$ ), but not white inmates ( $r=0.07$ , $p=0.74$ ) significant positive correlations between internalised stigma and stereotype agreement for white ( $r=0.53$ , $p=0.001$ ) and black inmates ( $r=0.44$ , $p=0.001$ )
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(Reinsmith-Meyer, 2008) USA	Cohort	N=25 (for stigma question)	Mean age=32.55±10.00 (range= 18.2-69.73)	Asked to select reasons for not participating in any programs, including "I was embarrassed to face the staff or volunteers"	MH and ASPD using the Personality Assessment Inventory (PAI) <sup>29</sup>  Substance dependence using the Texas Christian University Correctional: Residential Treatment Form, Initial Assessment (TCU-CRTF) <sup>30</sup>	-	Having MH symptoms only was positively correlated with endorsing the stigma item (r=0.468, p<0.05)  Endorsing the stigma item was marginally negatively correlated with having antisocial PD symptoms (r=-0.384, p<0.10) and marginally positively correlated with having schizophrenia symptoms (r=0.37, p<0.10)  Endorsing the stigma item was not significantly correlated with any other individual mental health, substance dependency or co-morbid disorder
		Adult inmates of a county detention centre with serious mental health and substance dependency problems	69.5% Male 30.5% Female  44% African-American 37% Caucasian 8% Mexican-American 8% Middle-Eastern 7.5% Hispanic 4.1% mixed race 4% Native American 2.9% Asian/Pacific islander 2.1% other race  9.8% anxiety 11.9% schizophrenia 19.1% depression 19.8% mania				

(Vogel, 2015) USA	Intervention	N=10 (baseline) N=6 (follow-up)	Mean age =43.5 (range=23-63)  100% Male	ISMIS <sup>2</sup>	Participation in intervention	Ending Self-stigma group intervention  x9 sessions	Only 3 participants completed 75% or more sessions  Post-treatment mean ISMIS was similar to pre-treatment mean ISMIS scores T1_Total_Mean= 2.16±0.15 T2_Total_Mean= 2.08±0.38  Means for both the Alienation and the Stereotype Endorsement subscales improved slightly after treatment T1_Alienation_Mean= 2.01 T2_Alienation_Mean=1.91 T1_Stereotype_Mean= 2.14 T2_Stereotype_Mean=2.04  Other subscale means remained constant or worsened slightly after treatment T1_Discrimination_Mean=2.16 T2_Discrimination_Mean=2.36 T1_Socialwithdrawal_Mean=2.05 T2_Socialwithdrawal_Mean=2.11 T1_StigmaResist_Mean=2.96 T2_StigmaResist_Mean=2.93  Post-treatment mean ISMIS was similar to pre-treatment mean. Means for both the Alienation and the Stereotype Endorsement subscales improved slightly after treatment. Other subscale means remained constant or worsened slightly after treatment.
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West et al (2015) USA	Cohort	N=82  (31 psychiatric hospital and 51 mental health court diversion program)	"middle aged"  70.7% Male 29.3% Female  37% Hispanic 35.8% Black/African-American 16% other race 7.4% white 1.2% US Asian 1.2% Arab/Middle-eastern 1.2% Native American  30.5% Schizophrenia 23.2% bipolar 17.1% schizo-affective 11% major depression 7.3% other psychotic 6.1% other mood	SSMIS <sup>28</sup> - stereotype concurrence subscale captures self-stigma re. MH.  EDS <sup>38</sup>  BACS-C <sup>39</sup> new subscale captures self-stigma re. criminal history.	Centre for Epidemiological studies depression scale (CES-D) <sup>34</sup>  Rosenberg self-esteem scale (RSES) <sup>5</sup>  Collective Self-Esteem Scale-Race/Ethnicity Version (CSES-R) <sup>40</sup>  Medication adherence rating scale (MARS) <sup>35</sup>  Psychological treatment compliance scale (PTCS) <sup>36</sup>  Working alliance inventory- short form (WAI-SR) <sup>37</sup>  .	-	SSMIS Self-Concurrence correlated positively with CES-D ( $r(79) = 0.33, p = 0.003$ ) and negatively with RSES ( $r(79) = -0.41, p < 0.001$ ) and MARS ( $r(78) = -0.34, p = 0.002$ ), but not PTCS.  SSMIS predicted self-esteem: $F = 3.93, p < 0.05$ (small es)  SSMIS Self-Concurrence x BACS-C correlated negatively with self-esteem.  BACS-C negatively correlated with total WAI-SR ( $r = -0.35, p < 0.005$ ), bond ( $r = -0.27, p < 0.05$ ), task ( $r = -0.38, p < 0.005$ ) and goal ( $r = -0.3, p < 0.005$ ) and positively correlated with SSMIS self-concurrence ( $r = 0.39, p < 0.001$ )  CSES Private negatively correlated with BACS-C ( $r = -0.322, p = 0.004$ )  CSES Private x BACS-C ( $F = 4.99, p < 0.05$ ) (moderate es) and SSMIS self-concurrence x BACS-C ( $F = 3.89, p < 0.05$ ) (small es) in predicting RSES.  CSES Private x BACS-C ( $F = 4.25, p < 0.05$ ) (small es) and SSMIS x CSES Private (moderate es) in predicting MARS-clinician.  CSES Private x BACS-C ( $F = 5.3, < 0.05$ ) moderate es) in predicting MARS-participant and RSES ( $F = 4.99, p < 0.05$ ) (moderate es)
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West et al (2018) USA	Part of West et al (2015) cohort study	N=82  (31 psychiatric hospital and 51 mental health court diversion program)	"middle aged"  70.7% Male 29.3% Female  37% Hispanic 35.8% Black/ African-American 16% other race 7.4% white 1.2% US Asian 1.2% Arab/ Middle-Eastern 1.2% Native American	TST <sup>41</sup>  ISMIS <sup>2</sup>  IPES <sup>42</sup>	Collective Self-Esteem Scale-Race/Ethnicity Version (CSES-R) <sup>40</sup>	-	Significant negative correlation between TST attribution and SSMIS self-concurrence (r=-0.237, p<0.05)  Significant positive correlation between TST global and SSMIS stigma agreement scale (r=0.289, p<0.01)  Significant positive correlation between TST global and IPES criminality self-stigma (r=0.319, p<0.005)  Significant association between total TST and IPES stigma awareness (regression controlling for covariates) (r=0.319,p=0.004)
<ol style="list-style-type: none"> <li>1. (Rotter, 1966)</li> <li>2. (Ritsher et al., 2003)</li> <li>3. (Kay, Fiszbein, &amp; Opler, 1987)</li> <li>4. (Amador et al., 1993)</li> <li>5. (Rosenberg, 1965)</li> <li>6. (Addington, Addington, &amp; Schissel, 1990)</li> <li>7. (Hasson-Ohayon, Kravetz, Roe, David, &amp; Weiser, 2006)</li> <li>8. (Shern, Lee, &amp; Coen, 1996)</li> <li>9. (Fischer &amp; Farina, 1995)</li> <li>10. (Cuellar, Arnold, &amp; Maldonado, 1995)</li> <li>11. (Eisen, Normand, Belanger, Spiro, &amp; Esch, 2004)</li> <li>12. (Becker, Diamond, &amp; Sainfort, 1993)</li> <li>13. (Gravel &amp; Béland, 2005)</li> <li>14. (Thomas et al., 2003)</li> <li>15. (Bullock, 2005)</li> <li>16. (Rogers, Chamberlin, Ellison, &amp; Crean, 1997)</li> <li>17. (O'Brien, White, Fahmy, &amp; Singh, 2009)</li> <li>18. (King et al., 2007)</li> <li>19. (Long et al., 2015)</li> <li>20. (Snyder et al., 1996)</li> <li>21. (Jerusalem &amp; Schwarzer, 1992)</li> <li>22. (Webster, Martin, Brink, Nicholls, &amp; Desmarais, 2009)</li> <li>23. (Dolan &amp; Fullam, 2001)</li> <li>24. (Lukoff, Neuchterlin, &amp; Wenture, 1986)</li> <li>25. (Moore, Tangney, et al., 2016)</li> <li>26. (Corrigan et al., 2006)</li> <li>27. (Diener, Emmons, Larsen, &amp; Griffin, 1985)</li> <li>28. (Seidlitz et al., 2002)</li> <li>29. (Morey, 1991)</li> <li>30. (Simpson &amp; Knight, 1998)</li> <li>31. (Mashek, Cannaday, &amp; Tangney, 2007)</li> <li>32. (Tangney et al., 2012)</li> <li>33. (Hart, Cox, &amp; Hare, 1995)</li> <li>34. (Radloff, 1977)</li> <li>35. (K. Thompson, Kulkarni, &amp; Sergejew, 2000)</li> <li>36. (Tsang, Fung, &amp; Corrigan, 2006)</li> <li>37. (Hatcher &amp; Gillaspay, 2006)</li> <li>38. (V. L. S. Thompson et al., 2004)</li> <li>39. (West et al., 2015)</li> <li>40. (Luhtanen &amp; Crocker, 1992)</li> <li>41. (Kuhn &amp; McPartland, 1954)</li> <li>42. (Mashek et al., 2002)</li> </ol>							

### **1.3.2 Quality and Risk of Bias Assessment**

All 13 included papers were assessed for quality and risk of bias using the 11-item tool detailed in Appendix D. Ratings were given according to the NICE quality assessment scoring system. A ‘++’ rating was given if that aspect of the study was conducted in such a way to minimise risk of bias. ‘+’ was given if the study has not addressed all potential sources of bias, or it is not clear from how the study is reported. ‘-’ was given if a significant source of bias was present due to an aspect of the study. ‘NA’ and ‘NR’ were given to questions which were not applicable or not reported to the assessment of the reviewed study.

Both the first and second authors assessed each of the included papers and initially agreed on 93% of items (Cohen’s Kappa=0.90). The remaining 7% of items where ratings differed were discussed until an agreement on the rating was reached. The results of the quality and risk of bias assessment are shown in table 1.4 for each of the 13 papers and 11 criteria. The overall quality of the studies varied, but most were of moderate quality, with cohort studies scoring more highly on methodological quality and being viewed as having less risk of bias than the intervention studies (taking into account those items which were relevant to both types of study).

All studies were deemed to have study designs which were appropriate to their research questions however, some reporting bias effected the quality of the studies in terms of reported and unreported results. The highest quality study had a sufficient sample size and power, identified and managed the effects of confounding variables and used valid and reliable measures of internalised stigma and other outcomes (Eno Louden & Manchak, 2018). The lowest quality study was deemed to have insufficient power, potentially inappropriate or missing analyses and unidentified or uncontrolled confounding variables (West et al., 2015). There was therefore assumed to be a risk of bias in terms of detection of effects and reporting of results.

Most studies used measures of internalised stigma that had been validated either in a mental health or forensic/criminal/offending population. More than half of the studies also used reliable tools to measure other variables and outcomes. Five out of the 13 studies

recruited samples which were deemed representative of their target population and selection bias was minimised.

For those studies not reporting pre or post-hoc power analyses, post-hoc analyses were conducted for this review using G\*Power statistical software package (Faul, Erdfelder, Buchner, & Lang, 2009). In general, studies were underpowered due to sample size and the number of variables analysed, however there were some analyses which had moderate and large effect sizes (Long et al., 2015).

Table 1.4 Quality Assessment of Included Studies

Study	Were there issues with the reporting of results such that bias towards certain findings was apparent?	Were the analytic methods appropriate?	Was the study sufficiently powered to detect an effect (if one exists)?	Was there significant issues with attrition to bias outcomes or comparisons?	Were the choice(s) of outcome measure(s) appropriate, reliable and valid?	Was the choice(s) of stigma measure(s) appropriate, reliable and valid?	How well were likely confounding factors identified and controlled for?	Were participants/ researchers blind to exposure and comparison and both delivered adequately?	Allocation to intervention/ exposure (or comparison) group. How was selection bias minimised?	Was the eligible population representative of the source population or area?	Was the study design appropriate to the research question?
Ali et al (2018)	+	+	NR	NA	+	+	++	NA	++	++	
Bentley& Casey (2017)	+	++	NR	NA	+	-	++	NA	+	++	
Dequelson et al (2015)	+	+	NR	NA	++	++	-	NA	-	++	
Eno Louden & Manchak (2018)	+	+	++	NA	+	++	++	NA	++	++	
Livingston et al (2011)	+	+	+	NA	++	++	++	NA	-	++	
Livingston et al (2013)	+	+	+	++	++	++	-	+	+	++	
Long et al (2015)	+	++	NR	++	++	++	+	+	+	++	
Moore et al (2017)	+	++	NR	++	++	+	+	NR	+	++	
Moore et al (2016)	+	+	+	+	++	+	+	++	+	++	
Reinsmith-Meyer (2008)	+	++	-	NA	++	+	++	NA	++	++	
Vogel (2015)	+	+	-	+	+	++	+	+	+	++	
West et al (2015)	+	-	-	NA	++	++	-	NA	++	++	
West et al (2018)	+	+	-	NA	++	++	+	NA	++	++	

### ***1.3.3 Narrative Synthesis of Key Findings***

Due to the wide-ranging variables included across the included studies, the findings could not be statistically synthesised or explored using meta-analytic methods. As this review aimed to explore the correlates and consequences of internalised stigma, the results described herein summarise the relationship between internalised stigma variables and other variables in the context of the included literature.

#### *Socio-demographic Factors*

Only one study reported on the relationship between internalised stigma and age. No significant correlation was found (Bentley & Casey, 2017).

Studies reporting on race relationships also found no significant correlation of self-identified race and measures of internalised stigma regarding mental illness (Bentley & Casey, 2017; West, 2015) or offending (Moore et al., 2017; Moore, Tangney, et al., 2016; West, 2015). Within sub-types of stigma, black but not white participants were found to experience more internalised stigma, the more they anticipated being stigmatised (Moore, Tangney, et al., 2016).

Having previously been homeless or incarcerated in the past was found to relate to more internalisation of mental health stigma (Livingston et al., 2011). Moreover, higher internalised stigma of mental illness was associated with longer incarcerations, but the number of incarcerations was unrelated (Bentley & Casey, 2017). Individuals' number of years of education or spirituality had no impact on internalised stigma (Moore et al., 2017).

#### *Mental Health and Wellbeing Factors*

In terms of the relationship between internalised stigma and mental health, the presence and severity of symptoms of a mental health problem were related to higher internalised stigma (Livingston et al., 2011; Reinsmith-Meyer, 2008). Nonetheless, there did not appear to be a cumulative effect of the number of mental health diagnoses (Bentley & Casey, 2017).

There was no significant correlation between symptoms of depression and the extent to which participants agreed with negative stereotypes about people with mental illness,

however higher levels of depression symptoms did relate to self-concurrence of these negative stereotypes (Livingston et al., 2011). Moreover, higher severity of depression symptoms related to more internalised discriminatory and alienating attitudes about people with mental ill-health (Dequelson et al., 2015).

Higher levels of overall symptoms of mental health also related to more internalised stigma about offenders (Moore et al., 2017). Similarly, features of anti-social personality disorder and Factor 2 symptoms of psychopathy (e.g. impulsivity, irresponsibility) were correlated with internalisation of offending stigma, but Factor 1 symptoms (e.g. lack of remorse or guilt, lack of empathy) were not (Moore et al., 2017). Dependency problems with substances were not found to associate with internalised stigma (Moore et al., 2017; Reinsmith-Meyer, 2008). This review also found evidence to suggest that internalised stigma of mental illness mediated the positive correlation between an individual's awareness of their symptoms and the severity of these symptoms (Dequelson et al., 2015).

More generally, participants in Livingston et al.'s (2011) study were found on average to report higher wellbeing and life satisfaction with less internalisation of mental health stigma. In contrast, Moore et al (2017) found no significant associations between internalised stigma and life satisfaction.

### *Self-esteem*

Four included papers reported on the relationship between internalised stigma and self-esteem (Dequelson et al., 2015; Moore et al., 2017; Moore, Tangney, et al., 2016; West et al., 2015). One paper found no significant correlation between internalised stigma of mental illness and self-esteem (Dequelson et al., 2015), and two papers found they were negatively correlated, such that higher levels of internalised stigma were associated with lower self-esteem (Moore, Tangney, et al., 2016; West et al., 2015). Also, Moore et al (2017) found that higher self-esteem before mental health service involvement predicted lower levels of internalised stigma one year on. In addition, lower average self-esteem was associated with more self-concurrence with negative stereotypes about people with mental ill-health (West et al., 2015)

In terms of internalised stigma of negative beliefs about offenders, West et al (2015) found that when collective self-esteem was lower, beliefs were more salient. Furthermore this paper found that the interaction of internalised negative beliefs about offenders and those with mental illness significantly predicted self-esteem.

Sense of self (also termed 'self-concept') was assessed by one study using the Twenty Statements Test (TST) (West, Mulay, DeLuca, O'Donovan, & Yanos, 2018). The participants gave, on average, more attributive responses (i.e. referring to ways of behaving or feeling), the less they self-concurred with negative stereotypes of mental ill-health (small effect). Global responses (which see the respondent referring to the self in ways that are universal, such as 'human') correlated positively (and significantly) with a measure of agreement with negative stereotypes of mental ill-health as well as awareness of negative stereotypes of criminals and the extent to which the negative self-concept of being a criminal was internalised (West et al., 2018).

#### *Treatment, Intervention and Service Effects*

Whether compulsory treatment was received via civil or forensic mental health services had a negligible impact on levels of internalised stigma (Livingston et al., 2011).

On average, the more people reported self-concurring with mental health stereotypes, the poorer their adherence to medical treatment. The same was not found for adherence to psychological treatment. Better medication adherence was also predicted by the interaction of higher self-esteem and lower internalised mental health stigma (West et al., 2015). Better clinician and patient-reported medication adherence was also predicted by higher self-esteem interacting with internalised criminality stigma (West et al., 2015).

Regarding the therapeutic working alliance, poorer alliance was associated with higher levels of internalised criminality stigma (West et al., 2015). This significant correlation was also found within the subscales of working alliance, such that higher levels of internalised criminality stigma related to the development of a poorer therapeutic bond and poorer agreement between clinician and patient on the tasks and goals of therapy (West et al., 2015).

Three of the intervention studies reported similar or non-significant differences in levels of internalised mental-health stigma following treatment (Livingston et al., 2013; Moore, Stuewig, et al., 2016; Vogel, 2015). In terms of stigma sub-scales, the extent to which people with mental illness felt alienated or endorsed stereotypes of mental illness improved slightly following the 'Ending self-stigma' intervention, but others stayed constant or showed a decline following treatment (Vogel, 2015). In contrast, the 'Understanding Personality Disorders' psychoeducation intervention was associated with a reduction in mean disclosure score, meaning that people would be less concerned about disclosing they had a mental illness. However, this was also noted in a minority of individuals who were classed as 'non-completers' (Long et al., 2015).

Within the three-group Livingston et al. (2013) intervention, participating in a peer support group did relate to a reduction in internalised mental illness stigma, although this same impact was not seen with participation in the other groups making up this intervention (i.e. patient advisory committee or peer research team).

The level of participation in the intervention did not make a significant impact on internalised stigma between baseline and follow-up time points (Livingston et al., 2013; Vogel, 2015).

#### *Stigma, Identity and Attitudes*

In terms of identifying as a criminal, level of internalised stigma was not found to have an impact, nor did it impact participants' attitudes towards others who had committed crimes (Moore, Tangney, et al., 2016). Stigma was also not found to impact on how connected participants felt with the wider community (Moore et al., 2017).

Within stigma variables, positive correlations were found between internalised criminality stigma and criminal stereotype agreement (Moore, Tangney, et al., 2016) as well as mental health stereotype self-concurrence (West et al., 2015).

## 1.4 Discussion

### ***1.4.1 Summary of the consequences and correlates of internalised stigma***

The results of this systematic review add to the current literature around how stigma types operate in a forensic mental health population. Internalised stigma was found to correlate negatively with self-esteem, medication adherence, treatment alliance and having been homeless or incarcerated in the past. It was also found to be negatively associated with participation in a peer support group and positively correlated with mental-health symptom severity.

### ***1.4.2 Comparisons with Past Findings and Recommendations***

Experiences of discrimination attributed to mental health and offending were apparent in the included papers' samples. West et al. (2015) gave a descriptive summary of these such that 47.5% of participants reported experiencing discrimination due to their mental ill-health and 40.7% due to their incarceration. In addition, racial discrimination was reported by over half of this study's sample, supporting evidence that individuals often experience the impact of multiple stigmas (West et al., 2014). While perceived stigma was more likely to be given as a reason not to have mental health treatment by a criminal population compared with a civil population (Ali et al., 2018), where the mental health care was received (i.e. in general or forensic services) had no impact on internalised stigma (Livingston et al., 2011). This might contradict evidence of the detrimental impact of having multiple stigmatised identities. However, no definitive conclusions can be drawn from papers that did not target the study of multiple stigmas.

Overall, the included intervention studies showed a lack of significant change in measures of internalised stigma post-intervention (Livingston et al., 2013; Moore et al., 2017; Vogel, 2015). Two of the included studies which tested interventions which aimed to reduce internalised stigma in this population may have failed to have the desired effect by targeting processes that were not specific to how internalised stigma develops and operates in this population (Livingston et al., 2013; Vogel, 2015). Long et al. (2015) did report positive improvements in internalised stigma following their Personality Disorder psychoeducation group regardless of whether or not participants completed the group. It is therefore hard to conclude if the intervention itself played any part in reducing stigma, or if

another factor involved in participation, such as social contact or routine may have had a positive impact.

Findings confirmed conclusions from Livingston and Boyd's (2010) meta-analysis regarding internalised stigma's negative association with self-esteem (Moore, Tangney, et al., 2016) and part in self-concept (West et al., 2018). This also reflects Drapalski's (2013) internalised stigma model. Although one paper in this current review did not support this correlation (Dequelson et al., 2015), it is proposed that differences in study setting (i.e. hospital, prison) and culture (e.g. American, European) may partly account for this difference in findings (Livingston & Boyd, 2010). However, past research in this area highlighted that cultural differences in self-esteem need further investigation (Schmitt & Allik, 2005).

A common factor among the reviewed studies was that the levels of internalised stigma were found to be lower than expected for a population with at least two potentially marginalised identities (Moore, Tangney, et al., 2016; Vogel, 2015). This may raise questions regarding the need for research into internalised stigma in mental health or offending populations. However, due to a mixed-method study finding their qualitative results implied higher levels of internalised stigma than that measured quantitatively (Livingston et al., 2011), it is suggested that the tools used to measure internalised stigma are not sensitive to the processes which lead to the internalisation of negative stereotypes in that population. This may be due to the lack of available measures developed specifically for this population (Phillips, 2017), meaning that the effect of combined mental health and criminality stigma has been measured using tools designed only to focus on one of these contributing identities. Livingston et al. (2011) proposed that the generally lower-than-expected levels of internalised stigma may be more related to sampling and recruitment rather than limitations regarding outcomes measurement or intervention design. They suggested that individuals most likely to participate in the included studies were those who were also least likely to anticipate stigma, hence their participation. In this sense, those who internalised the most stigma about their mental illness and/or offending may have been less inclined to take part in the study or intervention, due to anticipating stigma in relation to participation.

In terms of social characteristics, this review found that longer incarcerations were related to higher levels of internalised mental health stigma (Bentley & Casey, 2017). This is suggested as supportive of past literature where those experiencing the most stigma had committed sexual crimes (Rade et al., 2016), which typically attract the longest custodial sentences (excluding life sentences) of all crime types (Scottish Government, 2016). Most of this review's included papers either found that internalised stigma was not associated with demographic variables, or the relationships were not explored, analysed or reported. Non-significant correlations with race (Bentley & Casey, 2017; Moore et al., 2017; Moore, Tangney, et al., 2016) and age (Bentley & Casey, 2017) reflected the findings of an earlier study (West, 2015). None of the included studies analysed gender differences in internalised stigma, potentially due to being limited by unequal gender splits in their recruited sample (Ali et al., 2018; Eno Loudon & Manchak, 2018; Livingston et al., 2013; Livingston et al., 2011; Reinsmith-Meyer, 2008; West et al., 2018; West et al., 2015), or having a single-gender sample (Bentley & Casey, 2017; Long et al., 2015; Moore & Tangney, 2017; Moore, Tangney, et al., 2016; Vogel, 2015). West (2015) did note that men tended to internalise more stigma regarding their criminality than women, although this analysis and finding was excluded from the later published paper from this thesis (West et al., 2015). Further exploration of how demographic variables associate with internalised stigma is warranted to gain a better understanding of these potential factors in forensic mental health.

This review supports previous findings about the relationship between internalised stigma and mental health. Some, but not all findings contribute to the argument that the presence and severity of mental ill-health is associated with higher internalised stigma (Livingston et al., 2011; Reinsmith-Meyer, 2008). Studies measuring factors pertaining to quality of life produced contradictory results (Livingston et al., 2011), which did not fit with suggestions that internalised stigma had a generally negative impact on wellbeing (Thille et al., 2017). In addition to the aforementioned differences in study samples, locations and cultures, it is likely that the variety of different tools used to measure internalised stigma (and the fact that less than half of these had good psychometric properties) accounts somewhat for these inconsistencies.

### **1.4.3 Implications on research and practise**

Due to the heterogeneity of study designs, interventions and measures used, it is difficult to draw any key conclusions from the included literature. In addition, measures of internalised stigma due to mental health and criminality were dealt with separately within the studies that explored both, meaning that the combined impact of the multiple stigma was not adequately measured in any of the papers. Furthermore, mental- health or offending labels are not expected to be mutually exclusive and could therefore skew scores on the outcome measures.

### **1.4.4 Limitations**

This review was limited by the search having only been conducted using English-language search terms. Although this review's screening and eligibility process resulted in the full-text retrieval of five papers written in languages other than English, there was no resource available for translation services, therefore only one paper was translated (Dequelson et al., 2015) by a student of Translation Studies at the University of Edinburgh.

This review is also limited by its definition of internalised stigma, due to the variety of tools then used to extract information pertaining to this as a concept. This echoes a limitation of the Livingston and Boyd (2010) paper, which reviewed mental health studies that used six different internalised stigma measures, as well as papers that had developed their own customised tools. A systematic review of internalised stigma instruments suggested that future tools should be developed according to a consistent and agreed conceptualisation of internalised stigma and only used for assessment in the populations where it was developed, or has since been validated (Stevelink et al., 2012). As different instruments may measure different constructs or domains of internalised stigma, the results cannot be reliably viewed as entirely representative of the same phenomenon (Livingston & Boyd, 2010; Stevelink et al., 2012). The present review's results and preliminary conclusions have made suggestions regarding the correlates and consequences of internalised stigma of mental illness and offending, based on scales and sub-scales that measure shame, embarrassment, stereotype agreement, stereotype self-concurrence and self-stigma. Nonetheless, based on the current literature, this is argued to be the most appropriate way to gather and consolidate this information, until the evidence-base becomes more homogenous in terms of definitions and measurement tools.

### **1.4.5 Conclusions**

In summary, this review included and reviewed 13 studies of varying quality in order to synthesize their findings via narrative description. It extends the evidence summarised in the Livingston and Boyd (2010) systematic review and meta-analysis by adding in the forensic element of the population to make this review unique. It also captured studies published post-2010 which this past review does not include. From this review's findings, it is recommended that more intervention studies are required to enable a fuller understanding of the elements of the interventions which are successful in reducing internalised stigma. Having more intervention studies in this area would enable a systematic review and meta-analysis to be conducted solely looking at the effectiveness of internalised stigma interventions. This proposal relies on intervention studies of adequate quality, for which Randomised Control Trials (RCTs) are most desired, and appropriate tools to measure outcomes pertinent to how internalised stigma presents in this population. Prior to this, it is deemed reasonable to suggest that further qualitative literature exploring internalised stigma in forensic/criminal mental health populations is required to give a basis to the development or adaptation of internalised stigma measures according to the manifestation of this construct in this unique population.

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## Chapter 2- What promotes well-being of older people in forensic inpatient settings? Perceptions from older inpatients and staff.

### **Authors**

Ms Jane-Louise Jackson<sup>1,2</sup>, Dr Ethel Quayle<sup>2</sup>, Dr Clare Neil<sup>1</sup>

### **Affiliations**

<sup>1</sup>NHS Forth Valley, <sup>2</sup>University of Edinburgh

### **Corresponding Author**

Ms Jane-Louise Jackson, Westburn Building, Falkirk Community Hospital, Falkirk, FK1 5SU

This chapter is written according to 'The Journal of Forensic Psychiatry and Psychology' author guidelines for review articles (see Appendix A), with the exception of presentation format, which has been carried out according to the University of Edinburgh's 'Standards for the Formatting and Binding of a Thesis' for postgraduate research theses and the inclusion of tables/figures within the text for ease of reading.

## Abstract

The typically chronic, complex and comorbid health needs of older people are balanced with risk management in a forensic context. Current models of wellbeing in this context promote the concept of recovery as living well despite the limitations of illness, which is akin to a values-based approach.

The aim of the current study was to construct a model of wellbeing specific to older people within forensic mental health inpatient settings. This was done using the constructivist approach to Grounded Theory Methodology, recruiting patients (over 55 years old) and staff from sites within three NHS Scotland health boards. The researcher interviewed ten patients individually and fourteen staff via three focus groups. Concurrent data collection and analysis led to the construction of the substantive theory, 'Becoming a Better Person' and a model comprising the core categories of social context, knowledge and skills, relationships, interests and health. Clinical implications include support for a values-based approach to care and working with older people to re-engage with their sense of self.

Recommendations for future research are based on the findings of this study, including the identification of gaps in knowledge. Further data could strengthen the proposed model.

**Keywords:** *Forensic, Mental Health, Wellbeing, Ageing, Grounded Theory, Qualitative*

## 2.1 Introduction

Mental health policy in Scotland was developed based on an approach to recovery defined as “...a way of living a satisfactory, hopeful and contributing life even with the limitations caused by illness.” (Anthony & Rutman, 1993, p. 15; Tilley & Cowan, 2011). Recovery in this sense has become an internationally recognised and advocated philosophy underpinning mental health policy in Scotland (Cleary & Dowling, 2009; Slade et al., 2014; Tilley & Cowan, 2011). The current mental health strategy outlines an ambition for individuals to have access to recovery-based services which promote the rights of the individual by involving them in decision-making about their care, treating them as experts about their own experiences and supporting them to take responsibility for their health choices (Kelly, 2006; Scottish Government, 2017; Scottish Recovery Network, 2015).

One way for mental health services to promote recovery is by offering care and treatment based on the CHIME framework: connectedness, hope, identity, meaning and environment (Slade et al., 2014). Although hope is considered imperative to recovery defined by this framework (Werner, 2012b), some healthcare staff expressed concerns that the recovery approach may instil false hope of a cure (Corrigan, 2004; Tilley & Asquith, 2008) and that individuals may feel that they have failed at recovery if they are not symptom-free (Mezey, Kavuma, Turton, Demetriou, & Wright, 2010). This concern may be of particular relevance to work with people with co-morbid physical health problems which may not be adequately addressed by the CHIME framework (McKenna, Furness, Dhital, & Ireland, 2014; Slade et al., 2014). In fact, a qualitative synthesis of mental-health recovery research found that one-third of the synthesised data was not represented by the existing CHIME framework and concluded that the concept of recovery should be expanded, in particular to consider difficulties such as financial concerns and co-morbid substance misuse more prominently (Stuart, Tansey, & Quayle, 2017). Worley’s (2017) findings support this as improved quality of life, self-efficacy and employment were found to contribute to successful recovery from substance misuse disorders.

The 2017-2027 Mental Health Strategy highlighted poverty as the biggest driver of poor mental health, which is likely exacerbated by employment inequality amongst those experiencing mental health problems (Scottish Government, 2017). The recovery model promotes equal-access to holistic health and social care services in order challenge

inequalities such as poverty and social inclusion and remove barriers to services which may reduce help-seeking behaviours (Scottish Recovery Network, 2015). In terms of forensic mental healthcare, Drennan and Alred (2012) acknowledged that services should address social disadvantages and consider individual integration into society, promote acceptance of the past and support personal change. Recovery approaches to mental health care in forensic settings which encompasses these elements are currently in place, with lower secure settings shifting focus away from biomedical models of care towards interventions which aim to prepare patients for moving back into the community, such as adjustment to environmental change and managing stigma (Khan, Maheshwari, & Vrklevski, 2018).

The assessment and management of risk to self and/or others is part of all mental health services' remits, although risk to others is more recognisable as an aspect of forensic mental health services. NHS Scotland's forensic services use a structured professional judgement (SPJ) model of risk assessment and management, including use of the HCR-20 to assess potentially contributing factors to risk of violence (Douglas, Hart, Webster, & Belfrage, 2013). A focus on such processes has been acknowledged by Clinical psychologists as contributing to risk-averse services, particularly where blame culture and lack of guidance contribute to staff reluctance to pursue positive-risk-taking scenarios with patients (Tickle, Brown, & Hayward, 2014). Positive risk-taking is imperative to recovery and rehabilitation which suggests that forensic mental health services prioritising risk management create barriers to the recovery approach (Reddington, 2017). Even though Khan et al.'s (2018) study noted that clinicians considered risk-centred forensic service models irrelevant, another recent study highlighted that successful recovery in forensic settings was measured predominantly in terms of public safety, despite patients and service providers aiming for a number of other outcomes (e.g. independent life, meaningful life) (Livingston, 2018). This literature seems to suggest a significant challenge in implementing recovery-based approaches to mental health care in forensic mental health settings.

Moreover, secure forensic settings are likely to care for patients under legal treatment orders, which can lead individuals to assume an environment of coercive care if they believe non-compliance will impact negatively on their progress (Gow, Choo, Darjee, Gould, & Steele, 2010). This is likely to impact on the implementation and success of the recovery

approach in forensic settings, where patients have been shown to focus on what they believe is realistic in terms of progress, rather than elements such as empowerment, control and personal identity, which may seem less achievable in a secure and restricted environment (Corlett & Miles, 2010). Feelings of coercion and lack of optimism regarding recovery is particularly salient if patients view it as a 'top down' approach, not grounded in their personal needs or values (Slade et al., 2014). This is more likely to come about where staff at all levels lack commitment to the implementation of recovery models or due to the increasing pressure on resources in the NHS, meaning otherwise-willing staff are too time-limited to implement recovery-based care (McKenna et al., 2014).

Where the recovery approach has been successful in forensic mental health has been in the development of the Good Lives Model, which outlines a more holistic approach to care than the traditional medical model or risk-focussed approach (Barnao, Ward, & Robertson, 2016; Ward, 2002). Although specific to the rehabilitation of those committing sexual offences, this model more generally fits with the recovery approach by promoting values such as community and agency, connectedness, freedom, hope and health which promote meaningful recovery in forensic mental health (Clarke, Lumbard, Sambrook, & Kerr, 2015). This model also informs interventions which aim to nurture pro-social attitudes whilst challenging factors involved in offending behaviours (A. I. Simpson & Penney, 2011; Ward & Fortune, 2013), highlighting the importance of the therapeutic relationship (Barnao, Robertson, & Ward, 2010). Staff have an invaluable role in the implementation and imbedding of a recovery-oriented care culture and inpatient settings present an ideal opportunity for staff to promote and model pro-social, caring, functional and collaborative therapeutic relationships based on trust (Drennan & Alred, 2012). Social bonding theory further evidences how inpatient settings can use the therapeutic relationship to aid recovery via attachment to others, learning and understanding social norms and taking part in socially conventional activities (Nijdam-Jones, Livingston, Verdun-Jones, & Brink, 2015). It seems key, therefore, that recovery research in inpatient settings should seek perceptions from staff and patients.

The World Health Organisation (WHO) (2015) projected that the average life expectancy of people living in Europe would reach 80 years by 2050. Unfortunately, there is little evidence that longevity is related to living with better health, meaning that there is an increasing

demand on health care resources as both the number and proportion of older people grows (WHO, 2016). This is likely to become a significant issue for forensic services, which literature already refers to as resource-intensive (Khan et al., 2018). However, the recovery approach could potentially reduce rates of re-admission in older people, if they are included in the planning and management of their care such that they are supported to live well with illness post-discharge (Kisely, 2017). In this way, the recovery approach reflects the gold standard of healthcare for older people and the World Health Organisation's health ageing model which recommends integrated services which help develop or maintain an individual's functioning to allow them do things they value, rather than focussing on eradicating disease (de Carvalho et al., 2017; Hilton & Hulman, 2010). This also complements the Acceptance and Commitment Therapy (ACT) model (S. C. Hayes, Luoma, Bond, Masuda, & Lillis, 2006) which suggests that the recovery approach encompasses values-based living (Harris, 2008).

Nonetheless, it is argued that current models of care do not fully consider, nor integrate the unique needs of an older population in forensic settings. Models of forensic mental health care have not been developed specifically for older people and they do not explicitly address issues regarding older people's more complex, chronic and unique needs in comparison to their younger peers (Girardi, Snyman, Natarajan, & Griffiths, 2018; Natarajan & Mulvana, 2017). UK research with older forensic inpatients in high secure hospitals highlighted a lack of understanding of their needs (Yorston & Taylor, 2009) and studies considering the applicability of the recovery approach highlighted that older people differed from their younger peers in terms of regaining or maintaining a sense of self rather than developing their sense of self (Daley, Newton, Slade, Murray, & Banerjee, 2013). Since then, a study found that older forensic inpatients were satisfied by their healthcare provision, but felt that psychological and practical support was lacking (Di Lorito et al., 2017). Similarly, a review of prison literature proposed that legal and social services are not set up for managing prisoners with dementia as staff do not have the required expertise (Cipriani, Danti, Carlesi, & Di Fiorino, 2017). Although not an inevitable part of ageing, rates of dementia would be expected to rise as the population ages and it is argued that current recovery models of care do not adequately address the need for resources and pathways for dementia assessment and management in secure settings.

Furthermore, although research interest has grown in response to the ageing population, stereotypical views about ageing (e.g. being a burden on services) remain (WHO, 2015). Older people involved with forensic mental health services may hold three disadvantaged identities based on stigma about age, mental health and offending, which research suggests can lead to health inequality, partially mediated by being exposed to multiple discriminations (Grollman, 2014). It is important to be aware that staff may hold potentially stigmatising attitudes as they are likely to influence their interactions (Lammie, Harrison, Macmahon, & Knifton, 2010; Slade et al., 2014) and can lead to discriminatory practises such as excluding older people from activities in favour of directing resources towards younger people with more behavioural problems (Fazel, Hope, Donnell, & Jacoby, 2001; A. J. Hayes, Burns, Turnbull, & Shaw, 2012; O'Hara et al., 2016). It is clear how this could in turn lead to social isolation, which is linked to loneliness and associated with generally poorer mental and physical health and increased morbidity in older people (Ellwardt, van Tilburg, Aartsen, Wittek, & Steverink, 2015; Nicholson, 2012; Poscia et al., 2018).

The current literature around the needs of older people in secure settings is limited by the lack of agreement on the age at which a person is considered 'older' (Natarajan & Mulvana, 2017), meaning the definition of an older forensic mental health inpatient is inconsistent between studies (Kakoullis, Le Mesurier, & Kingston, 2010). It is argued that biological rather than chronological age is a more useful definition, as it accounts for individual and group variations in the time of onset of age-related needs (Yorston, 2013) and does not imply that older people are a homogenous group (Werner, 2012a). However, a needs-based cut off would be difficult to define (Natarajan & Mulvana, 2017), therefore a chronological cut-off is used in the present study. Some prison researchers have lowered their cut-off age from the typical retirement age of 65 years, to account for 'accelerated ageing' experienced due to lifestyle, trauma, substance misuse, offending and illness-related factors (Baidawi, 2016; Baidawi et al., 2011; Collins & Bird, 2007; Ginn, 2012; A. J. Hayes et al., 2012; Mitka, 2004; Williams, Ahalt, & Greifinger, 2014). These have been suggested to increase the biological age by around 10-15 years (Mitka, 2004), which puts the cut-off age in line with that of third sector services such as RECOOP (Resettlement and care for Older ex-offenders and Prisoners) (Omolade, 2014). Nonetheless, prison studies involve people who experience environments which may contribute to accelerated ageing, more so than the forensic mental-health system (Anno, Graham, Lawrence, & Shanksy,

2004). Therefore, older adults are defined in the present study as people aged 55 years and over. This is in line with a current NHS Scotland study looking at the psychiatric needs of older forensic inpatients by authors of past research in this field (Lightbody, Gow, & Gibb, 2010; McLeod, Yorston, & Gibb, 2008) and is supportive of a preventative, pro-active approach to healthcare (Cooney & Braggins, 2010).

The present study is the first to explore the wellbeing of the older adult forensic inpatient population in Scotland using a Grounded Theory Methodology (GTM) to explore values and generate a theoretical model of wellbeing (Charmaz, 2014; Glaser & Strauss, 1967; Strauss & Corbin, 1998). By developing a theoretical model specifically for older people in forensic secure settings, this study could influence the direction of policy and service development. Should this study's results contribute further evidence for the use of a recovery-based approach to care, strategies consistent with living well with illness could improve outcomes and reduce re-admission rates for older people in forensic mental health inpatient settings.

## 2.2 Method

### **2.2.1 Grounded Theory**

The present study takes the form of a qualitative exploration using the constructivist-approach to Grounded Theory Methodology (GTM) (Charmaz, 2014). This is suggested as a useful research method when exploring a topic or population that has not previously been explored, or to develop a deeper understanding of a phenomenon. It is appropriate therefore to use this approach to explore the values of older people in forensic inpatient settings, as this particular group's needs are not fully understood. In addition, the GTM approach is helpful in exploring the meaning people attach to their experiences and analyse relationships between constructs and themes.

Constructivist GTM (Charmaz, 2014) was chosen for the current study as a way of collecting and analysing data such that the involvement of the researcher was acknowledged within the development of theory. This is particularly relevant to the current study as the researcher took on all roles involved in data collection and analysis, therefore considering the researcher as a neutral observer in the process would be unreasonable. The present study therefore treated this qualitative research process and resultant theories as a construction, occurring within the conditions of the study as a whole, rather than

understanding resultant theories as being solely discovered within or emerging from the data (Strauss & Corbin, 1998).

### **2.2.2 Participants**

This study recruited patients and staff from four sites across three NHS Scotland health boards (NHS Forth Valley, NHS Greater Glasgow and Clyde and The State Hospitals Board for Scotland). These sites consisted of wards within high (The State Hospital), medium (Rowanbank Clinic) and low (Bellsdyke and Leverndale Hospitals) secure facilities, recognised as such by the Forensic Mental Health Services Managed Care Network (Scotland).

Patients were invited to participate if they met the following inclusion criteria: forensic mental health inpatients, age 55 years or older, English-speaking and with the capacity to give informed consent. Nursing and Clinical Psychology staff identified which of their patients met this criteria and, out of the 27 patients identified across the four recruitment sites, nine were not deemed to have capacity by their Responsible Medical Officer (RMO), one was too unwell to participate, two were deemed inappropriate and five declined. Of the 10 patients who took part in the study, 40% were current inpatients of a low secure ward, 10% medium and 50% high secure. All were male, with a mean age of 59 years (standard deviation (SD)=3.45) and current admission length of between 4.42 and 21.52 years (mean=15, SD=6.13). Mental health diagnoses included schizophrenia (50%), bipolar affective disorder (20%), dependent or obsessive compulsive personality disorder (33.33%) and schizoaffective disorder (10%). 80% of patients had previous forensic mental health admissions, with an average (mean) of 26.75 years since their first admission date.

Staff were invited to participate if they met the following inclusion criteria: English-speaking with regular clinical contact with forensic mental health inpatients. Staff were invited via email and study-information presentations by the researcher and at multi-disciplinary team meetings by Clinical Psychology and Psychiatry colleagues. Fourteen staff meeting the inclusion criteria agreed to participate. Staff participants were 57% female and 43% male and had a mean age of 42.5 years (SD=11.1, range 24-59). Professions represented were Nursing (71.42%), Clinical Psychology (14.28%) and Occupational Therapy (14.28%) and

participants' years of clinical experience of working in forensic mental health ranged from one to 32 years (mean=13.70, SD=13.32).

### **2.2.2 Procedure**

Patients took part in this study via 1:1 unstructured interviews in quiet, private, clinical interview rooms within the ward where they were a current inpatient. Staff members participated as part of one of three focus groups (n1=5, n2=4, n3=5) run within private meeting areas in the wards where they worked. All participants were given the opportunity to ask questions regarding the study and re-read the information sheet, should they wish, prior to giving their informed consent.

For patient participants' 1:1 interviews, the researcher opened with the question "What is important to you?".

For staff participants, how the focus groups would be conducted was introduced based on guidance from literature (Finch & Lewis, 2003; Parker et al., 2012). Participants were invited to discuss, explore, agree, disagree and question each other's contributions. Participants were encouraged to voice their agreements or disagreements for the benefit of the audio recording, such that data formed an accurate representation of the discussion content. Prior to beginning the discussion, participants were given this study's definition of a forensic mental health inpatient, in part from the Forensic Matrix document 'For the purposes of this research, a forensic mental health patient has a history of contact with forensic services, mental ill-health and behaviour that has, or is likely to, put them in contact with the criminal justice service. "This includes adults who are subject to compulsory measures under mental health legislation and present a significant risk to others, such that they require care under conditions of security and/or specialist 'forensic' expertise in their management" ' (Forensic Network, 2011).

The researcher opened focus groups with the question "What do you think is important to older-adult forensic inpatients?".

Following both initial questions, open and flexible questioning continued to further explore meaning, impact, motivations, opinions and values, using techniques from Acceptance and

Commitment Therapy (e.g. use of metaphors) (S. C. Hayes, 2012). Participants agreed to be contacted for follow-up interviews and/or presentation of results, either via email (staff) or their keyworker on the ward (patients).

Patient demographic information was collected via an inpatient census carried out within The Forensic Network in Scotland in 2013. Staff participants were asked when they attended a focus group for their age, gender, profession and number of years' experience in a forensic setting. The impact on the results of this study from these variables was managed via exploration in interviews and ongoing revision of questions (e.g. exploring opinions on potential differences/similarities between settings).

### **2.2.3 Ethics**

Approval for the study was gained from the NHS West of Scotland Sub-Ethics committee (application via the Integrated Research Application System (IRAS)) and the University of Edinburgh's Faculty of Health in Social Science ethics committee. Research and Development (R&D) approval was awarded from each of the three health boards, in addition to Caldicott approval regarding dealing with patient identifiable information. See Appendices F and G for approval letters.

### **2.2.3 Analysis and Rigour**

Co-current data collection and analysis took place throughout the data collection period (November 2017-April 2018) on a combined dataset from the two data sources (patient interviews and staff focus groups). This form of triangulation enabled the researcher to constantly compare data and codes between the two data sources and notice where data was converging or diverging (Carter, Bryant-Lukosius, DiCenso, Blythe, & Neville, 2014). Subsequent interview/focus group questions evolved to further explore developing codes in context and to test and refine concepts. Data in the form of interview or focus group transcripts was initially coded line-by-line before undertaking focussed coding whereby initial codes from both data sets were grouped according to the purpose they served, their underlying meaning or representation of a construct which was developed via the raw data and researcher's memos (see Appendices K and L for examples). The researcher then questioned the relationships and interactions between these focussed codes and began to draw them together into categories and raise them to a higher level of conceptualisation by

constructing theoretical codes, according to their function and inter-relationships. Through continued use of memos (free-writing and clustering) the researcher captured initial ideas, interpretations, analyses and reflections from all parts of the data collection and analysis process.

A diagrammatic and narrative representation of the constructed substantive theory was shared with two patient participants and 12 staff participants such that feedback could be gathered. This allowed confirmation and adjustment of elements of the model as well as the overall lay out and readability.

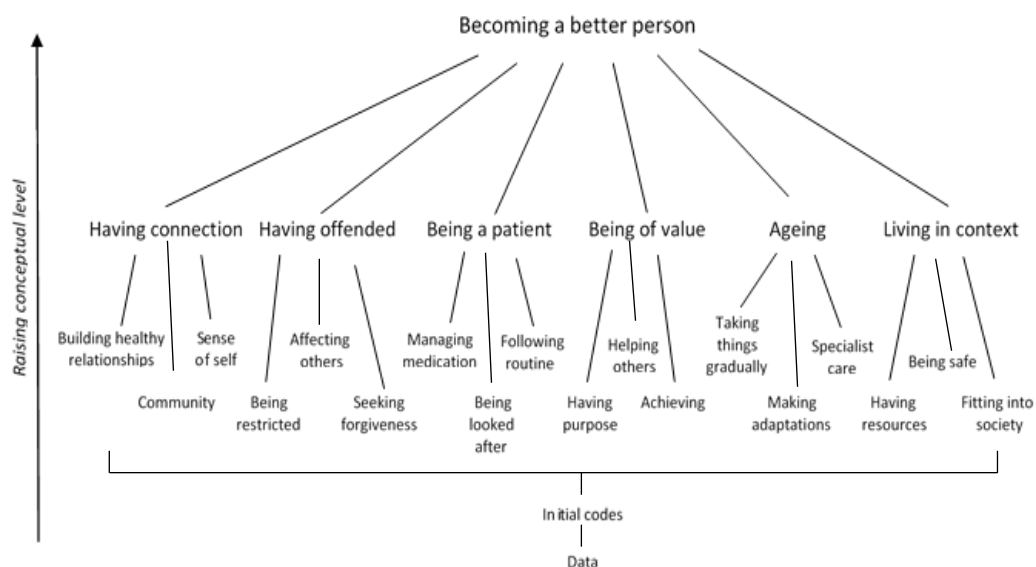
## 2.3 Results

The accounts of 10 patients and 14 staff gave information regarding their opinions about the factors involved in the wellbeing of older people in forensic inpatient settings. These accounts focussed mostly on the secure hospital setting in terms of the present context for the older people who were subject of this study, although detailed accounts were provided of past and potential future contexts, including lower secure settings and the community, and the relationships with the self and others in these settings. This study identified motivations and values within these accounts and drew inferences regarding meaning and underlying needs and processes from past, present and future orientated narratives.

### **2.3.1 Substantive Theory**

The substantive theory 'Becoming a better person' was constructed from six categories: being of value, having connection, having offended, being a patient, ageing and living in context. These categories were constructed from initial concepts developed from theoretical codes, focussed codes and memos, which are grounded in the data. These can be understood as representing values, served by related actions (e.g. the action of making positive lifestyle choices to serve the value of ageing well) which form processes. Figure 2.1 illustrates how the analysis raised the conceptual level from raw data to the substantive theory, by showing a sample of the theoretical codes which were used to construct categories, which in turn were used to construct the substantive theory.

Figure 2.1 Construction of Substantive Theory



### 2.3.2 Constructing a Theoretical Model

Concurrent coding and data collection meant that there was an iterative process such that initial and focussed codes were re-examined with the addition of new data. It was felt that the linear outline in Figure 2.1 did not adequately address the processes which encompass these categories, nor the inter-twining relationships between them. Therefore, further memos (clustering technique) were used to raise the conceptual level of the six categories such that the processes involved in moving from categories to the substantive theory could be more fully explored. The following narrative therefore makes reference to the categories in the context of the values and needs they represent, which related to patient wellbeing. This narrative includes direct extracts from participants' accounts, labelled 'S' to identify an extract from a staff focus group and 'P', an extract from a patient interview.

#### **Understanding and Processing**

Patient and staff accounts detailed a period of understanding and processing of events, behaviours and changes (internal and external) following admission which included, for example, coming to terms with their offence. This is also constructed as an ongoing process which occurs when there is a personal or systemic response to any individual or systems-level action or event.

For patients, the most salient codes relating to the impact of their offending were around self-blame for the loss of their family, '...my family, they don't want to know, mainly because of what I done, it was a bad thing' (P6). 'I tried to contact him by mail but there was no answer...I just had to let it go...he'd moved away and not left a forwarding address... It's my fault for getting in trouble.' (P8). Understanding and processing these changes seemed important for patients, whose accounts detailed multiple losses, for example of their 'home' and 'belongings' (P2) due to their hospital admission and experiencing the death of parents (P1) and friends (P9) whilst admitted.

As well as loss of connections and resources, patients noted that they had 'missed a lot' (P5) due to their time in hospital, or that it had '...been a waste of life and these years with x I'll never get back.' (P1). This sense of regret sat alongside feeling that it was important to seek forgiveness for their offence(s) and not 'make that mistake again' (P7).

Patients spoke about learning and understanding the role of 'being a patient'. This included managing medication, 'It's a little bit different. I mean, my medication has changed and I'm having to get used to that now' (P4) and the change in power balance that came with that, 'I don't agree that I need it, but I take it to keep them happy' (P1). Accounts also talked to the process of coming to terms with being separated from the community and the expectations of the hospital which had an impact on their sense of control, 'there's all these restrictions and that, thing you shouldn't be doing and you know going to programmes...placements...life's not your own' (P9).

The hospital community was seen to promote understanding and tolerance of others with different offending histories, 'It could be difficult you know, because people are here for horrendous things that have happened, including myself, so it can be a bit difficult at times...' (P7) and mental ill-health, '...shows you how a mental illness affects people in different ways' (P9). Patient accounts agreed that learning about other people's difficulties helped them also to understand themselves, particularly in terms of their past and current behaviour, 'I definitely understand myself more... In here you are helped to understand and try to understand why and the more you understand the healthier you're getting...' (P6).

### ***Reflecting on what Matters***

During interviews, patients reflected on their pasts and present and the open interviewing style was able to illicit from these accounts what mattered most to people in their lives. Where patients had experienced losses, for example of family and friends, making connections within the hospital environment seemed important, ‘...as some of them have been here a very long time, some of them don’t have contact with family anymore and it does become the ward, the staff and patients are a bit like their community, their family.’ (S3). Accounts implied that the hospital community nurtures opportunities to develop and maintain healthy relationships and negotiate difficult relationships, which is likely to aid people moving forward.

Patients expressed the need to have more time alone as they got older, but considered a ‘...a bit of both...’ (P5) important for wellbeing. Within the hospital context, individuals have access to other people at all times and are encouraged to socialise. Along with feeling connected to a sense of self and other people, participant accounts also included enjoying a connection with animals, such as past pets and caring for animals in hospital, as part of their rehabilitation, ‘I help to clean that out and learn how to hold them and that. You know, holding a wee animal-there’s something special about it...you know it’s trusting you...’ (P7).

In terms of recidivism, staff and patients agreed that risk changes with age (i.e. what was noted was a typical reduction in violent risk with increased frailty). This change seemed to apply also to how others view an older person who may have offended some time ago, such that, ‘Anyone looking at him now would turn around and say “nice wee fella”...’ (S2). This aligned with patients’ desire to be, ‘treated as the person [they are] now’ (P4), rather than the person they were following their offence, ‘I was looking in the mirror and I wasn’t seeing me...’ (P5), ‘I looked terrible...didn’t eat, didn’t sleep, didn’t do anything...’ (P4). In addition, patient accounts often spoke of past and present actions which implied that they were wanting to be seen as more than their forensic mental health inpatient identity. It was hypothesised that by telling the researcher about past successes, patients felt valued, ‘I’ve got a certificate...I did a course and I passed the course. I’ve got it in my room, I show the staff and all that’ (P10). Having positive elements of themselves or their lives recognised seemed to be a clear promoter of wellbeing, although staff acknowledged that recognising

good work did not come naturally: 'we see it, but we probably never take time to complement each other about look what we've done' (S1), particularly in Scottish culture: 'it's a very Scottish thing as well that we don't say well done to ourselves' (S1).

Many patients talked positively about their past working lives, 'I was really good at my job' (P1), and recalled previously being involved in work within the hospital. Since this had been disallowed, patients reported missing the social elements of the work, as well as the sense of making a voluntary contribution to their community. Nonetheless, patient accounts detailed other activities within the hospital and rehabilitation context which provided a sense of purpose and of 'just being useful, you know, rather than just hanging around' (P7). This fits with the notion of 'Keeping busy and keeping myself healthy...' (P6) which most patients deemed a factor in promoting wellbeing, particularly if there was a variety of 'different things' (P8) available. It was acknowledged, however, that pacing was important as 'Sometimes it gets a bit strenuous' (P4).

### ***Accepting and Adapting***

Accepting and adapting to one's changing identity was seen as impacting on the wellbeing of older people, who had now identified some of what mattered to them most. This, and 'Reflecting on what matters' were seen as bidirectional processes, with patient accounts suggesting that their journeys were not, and are not, linear, such that reflection on values, making adaptations and accepting what has been, is an ongoing process.

Hospitals were seen as good at encouraging patients to take responsibility for their own health and wellbeing, which is key when considering the increased physical health needs in the older population. Healthier lifestyle choices were promoted across the different levels of security, including encouraging grounds or gym access for exercise and eating and sleeping well. Reflections by participants on the smoking ban within the hospitals concurred that, once adjusted to, it had had a positive impact on people's physical health, "...at the time we were against it...but I'm pleased ...that's the best thing they've done for me. I wasn't a heavy smoker but I'm glad...they saved my life basically...one of the best decisions I've ever come across and I'm grateful for that now.' (P7). Patients spoke about keeping themselves well, '...relaxation every morning...open the window, get fresh air, listen to the birds tweeting and think of somewhere nice that I've been before' (P10) as

well as connecting with other patients and having fun (via group activities or socialising), 'I found out that I'm very creative...that's mellowed me out, getting me in the right direction...' (P7).

In terms of self-concept, there was a sense that some patients talked about the parts of their character and experiences that would portray them as separate from the 'offender' label. This, at times, took the form of patients expressing negative attitudes towards other patients regarding their backgrounds, '...I didn't mix with a lot of the people that I find myself in this ward with...I'd always worked. A lot of the boys have never worked, survived on benefits or some come alone with, I think you call them forensic histories, criminal histories' (P3). Other ways people set themselves apart from others was by mentioning their unhealthy lifestyle choices such as being 'involved in illegal substances' (P2), or the nature of their offence, 'I'd not share a table with a sex offender' (P4).

A sense of being of value to others and having a purpose was obtained through being able to help or give to others, particularly friends and family. The hospitals facilitated this by providing opportunities to be creative which, for some allowed them to re-connect with past skills and pursue their interests, 'It's doing something for my family which they like and that's really nice. You feel better in yourself, do you know what I mean? It's really good' (P9). Similarly, older people's accounts implied that they gained a sense of satisfaction and self-worth from sharing their knowledge and experience with the younger people on the ward. 'I think because I've been in so long I can give a bit of advice that makes them feel that wee bit better...I'm good at giving advice and they really appreciate it. And they're all younger than me...so it's good' (P7).

Opportunities to pursue an education and/or further qualifications were mentioned across all secure levels, with hospitals and educational establishments being successful in managing the limitations of participating in distance courses within this context. Some patients noted that their education was a continuation from the 'degrees before I was incarcerated' (P3), whilst others described benefitting from education for the first time: 'Well, I never really had a real education until I came here and I've learned a lot' (P5). Being educated implied being of value in patient accounts, particularly where learning and

studying was deemed to contribute to a better future, 'I'm studying so I can be a Librarian in here' (P4).

Difficulties with decision-making and lack of confidence were apparent, which was seen to limit both progression and wellbeing, due to undermining a need for choice, autonomy, opportunity and achievement. This, in part, is likely to be due to the typically long admissions experienced by older people, which patient accounts suggested led to people being institutionalised, '...I've been in a long time and institutionalised and you've not been outside and you've been away for a long time.' (P10). Accepting the role and identity of 'being a patient' seemed to create an exaggerated sense of older people needing and relying on other people to develop a routine and make decisions, '...they don't know how to make decisions, "everyone else makes decisions for me"...' (S2). Perhaps understandably, older people were then observed by staff as 'needier' (S3) due to seeking permission and reassurance much more than other patients (who had experienced shorter admissions).

### ***Thinking about the Future***

In general, the topic of moving on through the system (i.e. down security levels) or out into the community was met with mixed feelings from both staff and patients and raised questions regarding positive risk-taking, for example, '...do we not take that risk, not because it's not good for the patient, but because it's not good for us?' (S2).

Although most staff agreed with older patients 'having come a long way' (S1) since admission, some older people felt undeserving of moving forward and back into the community. In contrast, others talked about feeling punished by 'having time-out removed' (P1) leading to a sense of confinement and having longer-term restrictions, including post-discharge, when compared with their peers in prison: 'In prison if you'd done all these years, you'd be out with no restrictions...' (P9).

Patients and staff agreed that individuals move through the mental health system and into the community gradually according to graded rehabilitation goals. Patients referred to building back up 'Stage by stage' (P9), which seemed of particular relevance to this older population, in part due to their typically long admissions. Patients related their long admissions to a more embedded sense of self as a patient and '...diminishing hope...' (P3)

for the future. Moreover, data contained suggestions of passivity regarding health and moving forward, implying that it was the hospital, rather than the individual that was in control, 'Hopefully I'll be out of here in x years. It's up to them...' (P9). Staff observed some patients increasing their risk-taking to slow progress and patients noted they did that by not participating in groups, 'I refused to do it for a lot of years and that's why I've been in for so many' (P5). Others explicitly communicated their wish to stay in hospital, '...I'd want to stay here. Do you know what I mean, because I'm used to here' (P4). This may imply that these patients identified with a 'sick role', which staff described as '...difficult to tackle' (S2) and, relevant to older people with long admissions, 'when it's engrained, it's harder to change' (S3).

For some, age was a barrier to moving on, as they felt their time to rehabilitate back into the community had passed, 'No. it's too late. By the time I'm out I'll be...Too old by that time. Others want to get out but I don't really want to, to tell the truth...' (P8). Other patients identified feelings of apprehension in relation to moving on following long admissions, 'how do you say it...it's daunting. There's things I've not thought about' (P4). For others, who implied enthusiasm and willingness to re-engage with the community, some considered their age as a barrier to obtaining work, 'Well I'll not be able to get a job when I get out at x age' (P4). For others, values-driven actions to gain a sense of purpose and meaning took the form of paid or unpaid community work. Similarly, some patients talked of 'owing society a lot' (P5) and wanting to give back to the community, for example by being '...fully involved with my church' (P2). Others implied a motivation to help those experiencing similarly adverse upbringings to themselves, 'I'd try and get them and give them a chance that I never had when I was a kid' (P10).

The therapeutic relationship was seen as an opportunity for modelling healthy and respectful interactions, guided by explicit and consistent boundaries set by staff. This was considered helpful to people in moving forward, as patients knew what was expected of them, 'I'd prefer if you knew where you were...rather than one Nurse say one thing and one Nurse say another' (S2), understand the system and how they might move through it, if they hadn't done so already, '...like to know where you stand and what to do to stick by the rules...' (P5). This seemed to encourage more active participation from some patients, 'I'm going to nip up and see them and find out what's involved... ...what to expect in the

community and in the x what to expect' (P5), although others remained passive regarding their future, for example: '...you just have to soldier on' (P2); 'I'll take it as it comes, you know...' (P4); '...getting on with my time...' (P8). Some patients showed a pessimistic outlook, 'Not much to look forward to either in the hospital or outside, assuming I do get released...' (P3) which made staff '...feel quite hopeless...' (S2). However, it appeared that pessimism had a protective function for wellbeing, 'I take a pessimistic view and you'll never be troubled by what comes along' (P5).

Regarding family, people recognised that they wanted to re-connect both with a sense of themselves in their family role (i.e. dad, husband, brother, son) and with their wider family network, including those who may have found it difficult to remain in contact during their hospital admission, or to understand their offence. Although participant accounts referenced family, it was also recognised that older patients had smaller social and family networks, with some reporting they had 'no one there' (P1). Looking forward, social isolation, particularly within the older population is a significant issue in the community. However, in both cases (i.e. those with and without community connections), staff and patient participants agreed that their connection to the hospital community was very important, even following discharge, 'that connection goes on and on and on for years' (S2).

### ***Ageing***

There were mixed views among patient participants regarding their identity according to age, but most accounts inferred that these patients were seen as older by their peers, 'I just need to accept it. I mean, I'm the oldest one in here you know, so the guys look at me and they call me auld yin' (P4). Both staff and patients acknowledged that they had aged together, particularly amongst those staff members who had spent many years working in the same setting, 'We kinda grow old with the guys as well' (S1). Nonetheless, negative attributions about ageing remained such that individuals were thought to lack confidence and direction as, 'they probably feel they are Jurassic' (S1) and are 'too old' (P1) for physical activities.

In general, staff tended to think less about chronological age in terms of their use of the older label, '...it totally depends on how they function...It doesn't dawn on me that often to

class them as an older person because they are managing their day really independently, they're doing things that any younger person would do without any support' (S3). Similarly, staff found that some patients seemed older than their years, 'one of the things about here is that people can look much older than they are' (S3). This seemed to contribute to mixed opinions regarding whether or not older people required specific services or wards separate from younger people in cases with complex physical and co-morbid health needs. It was hypothesised that age-segregated-care provision could be to the detriment of other categories such as connection and being of value. Patients themselves noted benefitting from younger patients' more up-to-date knowledge of the community and technology, as well as practical support, 'there's load of guys in here that are really nice young guys that could carry the bags for them' (P7).

Both patient and staff accounts acknowledged that older people likely require more resources and that forensic mental health is 'already quite a resource intensive service' (S2). Although some disagreed that specialist older people's activities were required, the current provision was acknowledged as being, 'catered for fitness, young people, sport...they're not catered for people that are [...] elderly' (S1). Similarly, many of the patients reported not identifying with the substance-use problems of the younger generation, meaning that they might not attend groups as they 'don't see some of the things being discussed as their issues' (S1).

Access to functional aids was raised as an area for improvement as secure hospital settings, 'don't have the same links as some other hospitals in terms of just getting a bit of equipment the next day...have to order things...takes a while' (S3). In addition, shared concerns regarding cognitive decline in the older population raised questions about staff having the specialist training, knowledge and skills required to manage conditions such as dementia, '...need to do a bit of reading up on those conditions, especially as the condition progresses in these patients to know how best to Nurse them and manage them' (S3). The need to plan for the future care of this population and increase access to the required resources was acknowledged.

Staff tended to imply that the risk of recidivism reduced with age, however there were concerns raised about seeing this population as homogenous. Risk assessment and

management was and ongoing individualised process, although it was generally inferred that older people were more predictable and therefore less risky, as staff have 'known them for a long time' (S2). Patients tended to agree that their risk of recidivism had lowered or with age, such that one patient felt frustrated about the paperwork which does not allow for risk to have completely diminished 'all you've got down there is minimum risk, you've not got yes or no' (P4). Uncertainty about risk assessment was evident in dementia cases, 'like a sex offender with dementia...how do you then, what's the risk management process?' (S2), although others felt that with dementia came reduced risk if 'you can forget that you're the bad guy' (S2). Staff saw cases where personality factors facilitated non-violent risk as, 'up there with the trickiest to just be with...unlikely to assault anybody or anything like that but difficult to manage...' (S3). In addition, patients recognised that ageing has come with less worry regarding others' opinions of them, 'I don't very much care, I mean the guys talk about me all the time' (P4). This may suggest reduced inhibition, a contributor to risky behaviour.

### ***Social Context***

Participants agreed that wellbeing is promoted by living in a context that is inclusive of older people and supports them to live independently, with access to services, suitable housing and financial security, 'I had no money and I had no life' (P1). Patient experiences however implied that they anticipate social exclusion following discharge, in part due to stigma about mental health where 'some people outside ... don't really understand it much' (P9). Patients predicted that mental health stigma would impact negatively on their future work prospects, '...when they find out how many tablets you take...they're very reluctant to put you out there, know what I mean, to offer you a job' (P4). This, in turn, is likely to limit opportunities to take part in activities which are in line with the value 'Having a purpose'.

Linked to long admissions, staff shared that they found it important for the hospital environment to be 'a home for people more than anything else' (S2), which is routinely 'freshened up' (P1). The physical environment of the hospital wards differed between sites, however a common theme was that patients wanted to 'brighten the place up' (P7) and personalise their own space. In the community, accounts spoke to both the physical environment of a home, 'I didn't even have carpets' (P1), as well as its location 'closer to family' (P4). Although staff implied that patients saw the hospital as their home, patient

accounts were mixed, with some expressing a sense of home being in the community. This was reported to impact on wellbeing where hospitals were far from where someone would call home, meaning family and friends had to 'come from a bit of distance' (P4) to visit patients.

In terms of location, thought was given regarding access to appropriate services, including healthcare, as well as being close to places of worship and opportunities for social and purposeful activities, 'I do want to be back out in the community and back at my church. That's the most important thing to me' (P2). Patients also noted that access to outdoor spaces benefitted their wellbeing: '...even if it's pouring of rain, you're getting the fresh air and seeing the scenery...it's always helpful...' (P1). Staff accounts suggested a lack of knowledge regarding community provisions: '...are there resources that are appropriate for older people rather than you know, the 30-somethings?' (S2). These questions fit in with discussions regarding the appropriateness of seeing older people as requiring different resources and lower security levels detailed their ability to take a more flexible, person-centred approach, whereby, '...patients with individual needs and interests [and] I've taken them to specialist places' (S2).

The boundaries and restrictions were viewed as imperative to maintain the safe and secure environment that patients sought, following past community experiences whereby feeling unsafe led to social isolation, 'I was like a hermit in my house' (P9). As well as the '...structure and systems...' (S1), hospitals provide the aforementioned sense of community, which contributes to feeling safe, '...safety in numbers, you know' (P7). Looking forward, patients noted that they needed their community environment to be different to the past, in order to keep well, 'It's no good going back outside and going into the same environment again and going back to normal just locking yourself in your house and that' (P4).

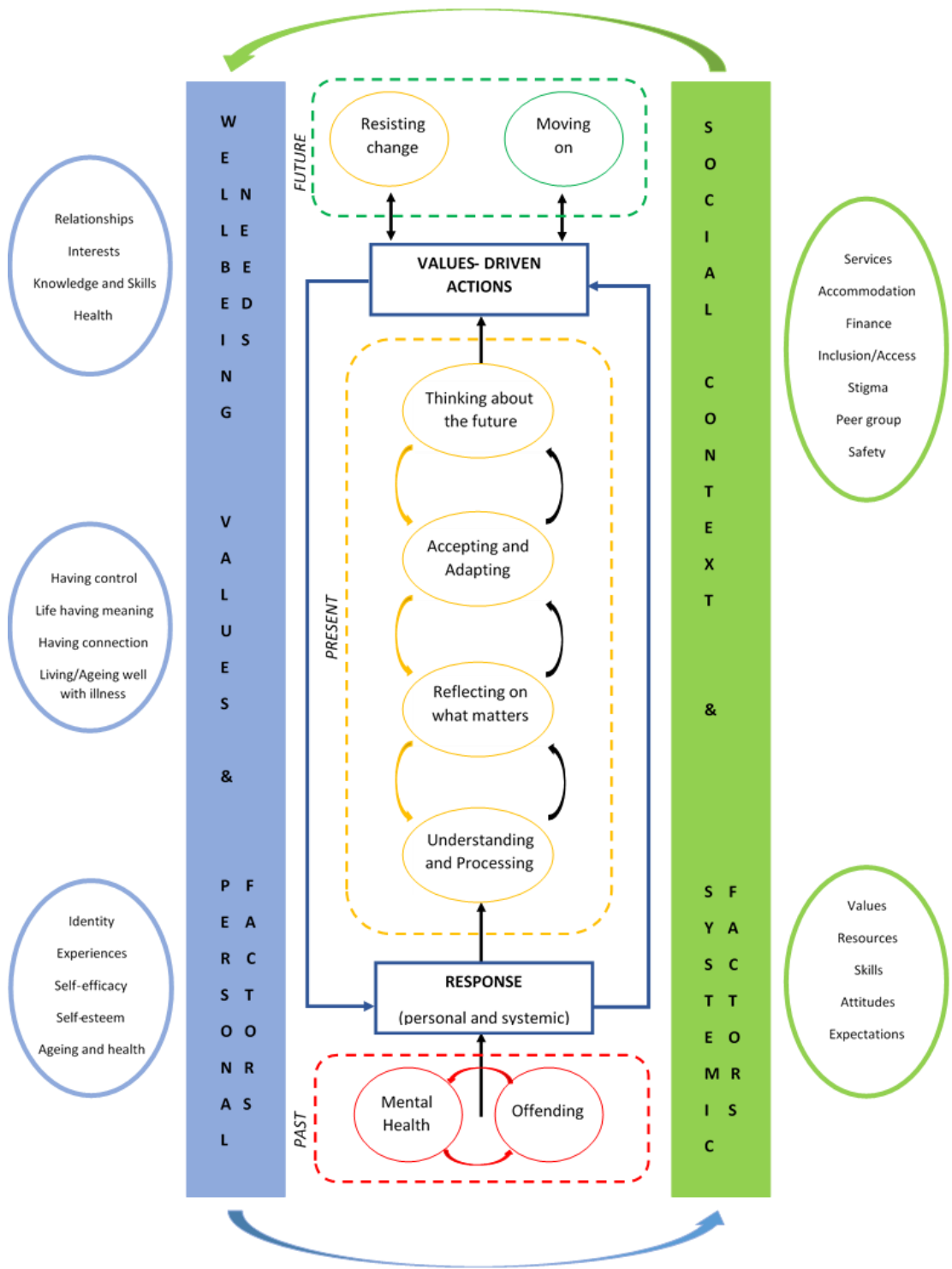
Participant accounts suggested that balancing support and structure with autonomy and choice felt like key elements of a wellbeing-promoting environment. In order to achieve this, it was felt that patients would need to feel like they would 'fit in in the community' (S1), which would help support a feeling of 'being of value'.

### ***2.3.2 Summary and Proposed Theoretical Model***

Diagrammatic representations of the proposed theoretical model were constructed and revised, with input from study participants, resulting in the model shown in Figure 2.2. This model illustrates the processes involved in the wellbeing of older people in forensic settings, as grounded in this study's data. Taking a past, present and future approach to displaying these processes, experiences and contributing factors makes use of all account orientations and enabled triangulation of staff and patient perspectives, particularly through processes of change.

Directional arrows enable the model to capture the experiences of those patient participants who expressed a wish to move on (through the system or out into the community) as well as those who wished to remain in hospital. The interdependent relationship between 'values-driven actions' and 'response' was constructed to represent how an individual acting in accordance to one value (e.g. allowing others to make decisions to feel of value), may be acting to the detriment of another value or values (e.g. having control) and, in turn, eliciting personal (e.g. strengthening the sick-role identity) and systemic (e.g. seeing patient as passive) responses. This, in turn could be followed by more values-driven actions, or begin the longer process of 'understanding and processing', 'reflecting on what matters', 'accepting and adapting' and 'thinking of the future'. It is proposed that both of these routes operate in support of the substantive theory 'Becoming a better person' and their success, in terms of wellbeing, is dependent on the presence, and positive fulfilment of the five core categories: relationships, interests, knowledge and skills, health and social context. Internal and external contributing factors are presented at either side of the proposed model, to represent their relevance throughout the older person's journey through the forensic mental health system.

Figure 2.2 Proposed Model of Wellbeing in Older Forensic Inpatients



## 2.4 Discussion

This study's results were used to construct a model of wellbeing in forensic mental health inpatient settings for older people. The identified values and needs share many of the elements of the Good Lives Model (Barnao et al., 2016), as well as categories which would fit within Mezey et al.'s (2010) offender recovery model, the original CHIME framework (Slade et al., 2014) and its proposed expansion (Stuart et al., 2017). As such, the model fits well with how forensic mental health inpatient services operate currently, although it takes the view of the older members of this population in Scotland, rather than generalising the values and needs of the whole population. In essence, the proposed model differs most by drawing attention to the management of more embedded personal and structural processes on individuals, the presence and impact of institutionalisation, more complex physical health needs, more limited future opportunities for work and increased stigma due to ageism. The core themes around purpose, community, agency and knowledge are shared between models, however, this model accounts for how these operate compared to one another as well as with the patient journey through the forensic secure mental health system (and potentially back into the community), which addresses some of the issues regarding adjustment and de-institutionalisation raised by Khan et al. (2018). This is a novel approach to promoting the wellbeing of older people in this context by highlighting the personal and systemic factors which aid people in moving forward, impede progress or increase risk of recidivism.

Developing and using knowledge and skills and having opportunities to pursue and enjoy interests were key to wellbeing. In addition, re-engaging with past activities and having opportunities to use previously gained knowledge and skills facilitated older people to regain their sense of self and feel valued and worthwhile. This reflects past findings (Daley et al., 2013). Giving back to the community and passing time in a way that is valuable to the individual was deemed supportive of healthy mental and physical health. In order for these factors to promote wellbeing, older people require access to opportunities in which to both use and develop their knowledge and skills, such as paid or voluntary work, training and education. This reflects past research, where balancing realistic expectations of what can be achieved within an individual's restrictions with increasing access to rehabilitation activities and taking more positive-risks was argued as key to the implementation of a model such as the present study's offering, in forensic settings (Corlett & Miles, 2010).

The hospitals where this study took place promoted the development of new knowledge and skills by encouraging people to undertake academic study and vocational courses online or, in lower secure settings, by engaging in accessible college classes. In addition, patient accounts suggested that hospitals promoted patient re-engagement with past learnt skills and interests, such that these became an established part of a person's routine again and promoted a sense of purpose. In turn, relationships between activity, work and community were constructed from the data as contributing to wellbeing. Most patient participants spoke about the social and emotional benefits of participating in creative activities since being in hospital, which adds to a 2011 systematic review which found inconsistent results regarding how these activities helped improve mental health (Leckey, 2011). The element each of these noted activities, group work or education have in common is the interpersonal contact, which fits in with the goal to reduce social isolation in older age (Poscia et al., 2018) and supports the argument for recovery-based services based on social bonding theory (Nijdam-Jones et al., 2015).

It is understandable that social context is important regarding having the logistical and financial means to participate in these opportunities. The link between mental health and social context was grounded in this study's data such that the presence of poverty, stigma and anti-social culture in the lives of older people were embedded in the processes which were reported as leading to relapse in mental ill-health and increased risk of recidivism post discharge. Participant accounts linked mental and physical health and talked about how each impacts on the other. This highlights the need to consider the impact of social context on both physical and mental health, including barriers created from a culture which advocates stigma (Corrigan, Druss, & Perlick, 2014). Such social processes are complex, but likely to mean that problems are exacerbated or, at least, perpetuated, unless services at all levels focus more on understanding their impact and supporting people to prepare for and cope with change (Khan et al., 2018). These findings also relate to the growing body of literature regarding the impact of UK austerity measures (Cummins, 2018; Stuckler, Reeves, Loopstra, Karanikolos, & McKee, 2017). However, a recent paper found that poverty was associated with lower psychological health service use, regardless of the level of service available, suggesting that how inequalities operate in healthcare is not straightforward and needs further exploration (Delgadillo, Farnfield, & North, 2018).

Data from the present study made salient the need for promotion of good physical and mental health and management and support for all health problems to enable better wellbeing. In an ageing population in particular, the focus was on the management of health problems such that a valued life could be lived despite long-term conditions or impairments. This reflects a recovery approach to mental health (Slade et al., 2014) and the current strategic direction for healthcare services (WHO, 2016). Research drawing attention to the more complex and co-morbid physical health needs of older people was confirmed by this study's findings, as was the existence of more typically 'older adult' health problems in people earlier in life, with participants recognising the contribution of past lifestyle choices (Baidawi et al., 2011).

Past researcher's lack of consensus regarding when someone should be considered 'old' was reflected within the context of this study (Natarajan & Mulvana, 2017). Some patient participants, although recognising that they were 'older' than their peers or 'the oldest' in the ward, did not identify themselves as 'old'. In addition, staff focus groups did offer discussions pertaining to past research suggestions about seeing older people as less risky, such that staff acknowledged that they were less-judgemental and less concerned regarding behavioural problems in their older patients (Fazel et al., 2001; A. J. Hayes et al., 2012; O'Hara et al., 2016). The patient accounts that contained references to being old also contained data which contributed to the development of categories related to increasing health needs. Although no definitive conclusions can be drawn from this limited qualitative study sample, these themes are in line with the proposal of a health-based definition of 'old age' rather than a, potentially benign chronological age cut-off (Yorston & Taylor, 2009). This would, in turn, open up specialist services to this younger-old age group of forensic patients who may be in need of care for typically 'old age' problems. Nonetheless, the hospital settings in which this study was based were reported to take an individual approach to care, such that the 'old age' label was deemed irrelevant in much of the focus group data. However, staff did recognise the need to develop their knowledge and skills regarding the typical health needs related to ageing, including dementia. This could suggest that forensic hospitals in Scotland may need to consider up-skilling their staff or employing specialist staff to manage the complexities of dementia in a forensic setting, along with the increasing physical co-morbidities. At present, staff reflections were that the proportion of

older people with these needs in their hospitals was not enough to warrant this. However, ageing was considered to be a shared process and Scotland's public services will be impacted by the public and their workforce ageing, further highlighting the importance of future workforce planning around elements such as capacity and skill-mix (Audit Scotland, 2017).

More generally, the secure hospital settings were said to play a positive role in promoting healthier lifestyles, including diet, exercise and stress reduction. These strategies are in line with Scottish Government recommendations for looking after the physical health of mental health patients (Scottish Government, 2008). In addition, the importance of therapeutic relationships was highlighted by both patient and staff accounts, which at times was described as key to maintaining an older person's sense of connection, social contact and family as well as enabling social learning regarding boundaries and trust. This reflects past research (Drennan & Alred, 2012) and would contribute more evidence to a recent systematic review which highlighted the salience of the therapeutic relationship within the broader social climate of forensic mental health (Doyle, Quayle, & Newman, 2017).

This study has a number of limitations, including in its application of the GTM (Charmaz, 2014). Although this method does not propose a minimum sample size, its aim of data saturation via concurrent data collection and analysis is core to the construction of a thorough theoretical model grounded in data from theoretically sampled participants. Due to limited resources, the researcher recruited by purposive and convenience sampling from secure sites in three different health boards. The potential number of participants expected from these three sites should have been such that theoretical sampling was possible, however more than 50% of the patients over 55 years old in the high and medium secure settings did not participate in this study. This significantly limited the population from which this study could recruit which meant that theoretical sampling was not possible and the sample sizes of both patient and staff groups did not allow for comparisons between participant characteristics (e.g. age, gender, secure level, profession, admission length, diagnosis). However, the impact of these characteristics were explored in interviews and many participants' accounts and opinions were informed by their experience or knowledge a setting other than their current ward.

As the initial decision regarding participation was made by ward staff, a degree of selection bias is likely. Although ethically appropriate, the proposed model may be lacking in the factors which promote wellbeing of those who were unwell at the time of the study, or those with dementia. This may limit the generalisability of the proposed model and applicability for those older than this study's oldest participant (age 65 years). The researcher attempted to mitigate this by asking staff to think about all patients over the age of 55 years, not just those eligible and able for participation in this study.

In terms of data saturation, the researcher conducted concurrent data collection and analysis according to the Charmaz (2014) constructivist type of GTM and triangulated the analysis of patient participant accounts with those from staff focus groups. Due to the aforementioned barriers to theoretical sampling, the researcher cannot confidently confirm that data saturation was reached, however ongoing construction of codes and categories did suggest that no completely new themes or concepts were being introduced by subsequent participants. Although follow-up interviews were not conducted (Charmaz, 2014), the researcher re-contacted staff participants and met with two patient participants for their views on the theoretical model and revised the model on the basis of these discussions.

The resource constraints may be seen to bring strength and rigour to this study, such that the first author had a close relationship to the data, due to maintaining engagement through every stage of data collection and analysis. This emphasises the suitability of using a constructivist approach to grounded theory, as the researcher's implicit biases and experiences are part of the model's co-construction as well as the data collection process (Charmaz, 2014).

This study's findings are argued as applicable to a rights and values-based approach to healthcare, due to identifying values specific to the older forensic population, such as being remembered as a good person, and re-connecting with their sense of self. This is likely to have clinical implications, as these findings suggest that interventions which aid patients in identifying and then living in accordance with their values may be effective in promoting wellbeing. In addition, findings suggest that interventions and policies are needed which target the structural, personal, systemic and cultural barriers to these values, for example

stigma, unnecessarily long admissions, psychological inflexibility and embedded 'sick role'. Findings also both highlighted difficulties arising from services' reluctance to taking positive risks with older people, answering questions raised by past studies.

In summary, the substantive theory 'Becoming a better person' was grounded in the interviews of 10 patients and focus groups with 14 staff within the context of forensic mental health secure wards in West and Central Scotland. The proposed model suggests a format for understanding the wellbeing of older people within these settings, which considers the factors involved with an individual's past, present and future and the transitions and interrelationships between these. By concurrent data collection and analysis and triangulation of patient and staff perspectives, this study constructed five categories representing personal values contributing to wellbeing and the factors detracting from wellbeing, which together map the stages of an older person's journey into and through the forensic mental health system: relationships; health; interests; knowledge and skills; and social context. The significance of these has been discussed herein and has been shown to relate to past literature and models of recovery (Barnao et al., 2016; Slade et al., 2014; Tilley & Cowan, 2011). Being aware of the methodological and other limitations of this present study, future research might be suggested to explore the applicability of this model with the demographic of patients who were not eligible for participation in this study (e.g. those with dementia) and with women. In addition, differences between settings may be further explored or accounted for by carrying out this type of study again within other health boards in Scotland and further afield. Nonetheless, this study's proposed model makes a novel contribution to this research area, such that the focus on wellbeing and ageing within this context has not before been studied qualitatively and, to the researcher's knowledge, no theoretical model specific to the wellbeing of older people in this context has been constructed in this way.

## 2.5 References-Chapter 2

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## Appendix A- Author Guidelines

Author Guidelines for 'The Journal of Forensic Psychiatry and Psychology' (original manuscripts and review articles only)

### **Instructions for authors**

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our Author Services website.

### **About the Journal**

*The Journal of Forensic Psychiatry & Psychology* is an international, peer-reviewed journal publishing high-quality, original research. Please see the journal's Aims & Scope for information about its focus and peer-review policy.

Please note that this journal only publishes manuscripts in English.

*The Journal of Forensic Psychiatry & Psychology* accepts the following types of article:

- original manuscripts
- case reports
- brief reports
- review articles
- book reviews
- review essays

### **Peer Review**

Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be double blind peer reviewed by independent, anonymous expert referees. Find out more about what to expect during peer review and read our guidance on publishing ethics.

## **Preparing Your Paper**

### *- Original manuscripts*

Should be written with the following elements in the following order: title page (including Acknowledgements as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

Should be no more than 5000 words, inclusive of the abstract, tables, figure captions, footnotes, endnotes.

Should contain an unstructured abstract of 200 words.

Between 3 and 6 keywords. Read making your article more discoverable, including information on choosing a title and search engine optimization. Please include a word count.

### *- Review articles*

Should be written with the following elements in the following order: title page (including Acknowledgements as well as Funding and grant-awarding bodies); abstract; keywords; main text; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figure caption(s) (as a list).

Should contain a structured abstract of 200 words.

Between 3 and 6 keywords. Read making your article more discoverable, including information on choosing a title and search engine optimization.

Review papers (e.g. systematic reviews, meta-analyses, law reviews) and some empirical studies may require greater length than regular articles and the Editors are happy to receive longer papers. We encourage brevity in reporting research. Please include a word count.

## **Style Guidelines**

Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy.

Any spelling style is acceptable so long as it is consistent within the manuscript.

Please use single quotation marks, except where 'a quotation is "within" a quotation'.

Please note that long quotations should be indented without quotation marks.

### **Formatting and Templates**

Papers may be submitted in Word format. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

Word templates are available for this journal. Please save the template to your hard drive, ready for use.

### **References**

Please use this reference guide when preparing your paper.

An EndNote output style is also available to assist you.

*Updated 16-05-2018*

## Appendix B- PROSPERO Registration

**PROSPERO**  
International prospective register of systematic reviews

  
National Institute for  
Health Research

**UNIVERSITY of York**  
Centre for Reviews and Dissemination

### Systematic review

#### 1. \* Review title.

Give the working title of the review, for example the one used for obtaining funding. Ideally the title should state succinctly the interventions or exposures being reviewed and the associated health or social problems. Where appropriate, the title should use the PI(E)COS structure to contain information on the Participants, Intervention (or Exposure) and Comparison groups, the Outcomes to be measured and Study designs to be included.

Consequences and correlates of internalized stigma in people with mental ill-health and contact with forensic services

#### 2. Original language title.

For reviews in languages other than English, this field should be used to enter the title in the language of the review. This will be displayed together with the English language title.

#### 3. \* Anticipated or actual start date.

Give the date when the systematic review commenced, or is expected to commence.

06/04/2018

#### 4. \* Anticipated completion date.

Give the date by which the review is expected to be completed.

31/07/2018

#### 5. \* Stage of review at time of this submission.

Indicate the stage of progress of the review by ticking the relevant Started and Completed boxes. Additional information may be added in the free text box provided.

Please note: Reviews that have progressed beyond the point of completing data extraction at the time of initial registration are not eligible for inclusion in PROSPERO. Should evidence of incorrect status and/or completion date being supplied at the time of submission come to light, the content of the PROSPERO record will be removed leaving only the title and named contact details and a statement that inaccuracies in the stage of the review date had been identified.

This field should be updated when any amendments are made to a published record and on completion and publication of the review.

The review has not yet started: No

Review stage	Started	Completed
Preliminary searches	Yes	Yes
Piloting of the study selection process	Yes	Yes
Formal screening of search results against eligibility criteria	Yes	Yes
Data extraction	Yes	Yes
Risk of bias (quality) assessment	Yes	Yes
Data analysis	Yes	No

Provide any other relevant information about the stage of the review here (e.g. Funded proposal, protocol not yet finalised).

**6. \* Named contact.**

The named contact acts as the guarantor for the accuracy of the information presented in the register record.  
Jane-Louise Jackson

**Email salutation (e.g. "Dr Smith" or "Joanne") for correspondence:**

Ms Jackson

**7. \* Named contact email.**

Give the electronic mail address of the named contact.  
s1580004@sms.ed.ac.uk

**8. Named contact address**

Give the full postal address for the named contact.

School of Health in Social Science  
Clinical Psychology  
Doorway 6, Medical School  
Teviot Place  
Edinburgh  
EH8 9AG

**9. Named contact phone number.**

Give the telephone number for the named contact, including international dialling code.  
+44 (0)1316 511619

**10. \* Organisational affiliation of the review.**

Full title of the organisational affiliations for this review and website address if available. This field may be completed as 'None' if the review is not affiliated to any organisation.

University of Edinburgh / NHS Forth Valley

**Organisation web address:**

**11. Review team members and their organisational affiliations.**

Give the title, first name, last name and the organisational affiliations of each member of the review team. Affiliation refers to groups or organisations to which review team members belong.

Ms Jane-Louise Jackson. University of Edinburgh / NHS Forth Valley  
Miss Julie Riddell. MRC/CSO Social & Public Health Sciences Unit, University of Glasgow  
Dr Ethel Quayle. University of Edinburgh  
Dr Clare Neil. NHS Forth Valley

**12. \* Funding sources/sponsors.**

Give details of the individuals, organizations, groups or other legal entities who take responsibility for initiating, managing, sponsoring and/or financing the review. Include any unique identification numbers assigned to the review by the individuals or bodies listed.

Ms Jackson is a Trainee Clinical Psychologist funded by the National Health Service (NHS) Education for Scotland (NES) via NHS Forth Valley and the University of Edinburgh.

**13. \* Conflicts of interest.**

List any conditions that could lead to actual or perceived undue influence on judgements concerning the main topic investigated in the review.

None

**14. Collaborators.**

Give the name and affiliation of any individuals or organisations who are working on the review but who are not listed as review team members.

**15. \* Review question.**

State the question(s) to be addressed by the review, clearly and precisely. Review questions may be specific or broad. It may be appropriate to break very broad questions down into a series of related more specific questions. Questions may be framed or refined using PI(E)COS where relevant.

What are the consequences and correlates of internalized-stigma for people living with mental illness who are in contact with forensic services?

**16. \* Searches.**

Give details of the sources to be searched, search dates (from and to), and any restrictions (e.g. language or publication period). The full search strategy is not required, but may be supplied as a link or attachment.

Databases searched: PsycINFO, Embase, Ovid MEDLINE (R) In-Process & Other Non-Indexed Citations and Ovid MEDLINE (R), Ovid MEDLINE (R) Epub Ahead of Print and Ovid MEDLINE (R) Daily; International Bibliography of the Social Sciences (IBSS); Applied Social Sciences Index and Abstracts (ASSIA); Social Services Abstracts; PAIS International; Criminal Justice; Dissertation and thesis global; and CINAHL.

**17. URL to search strategy.**

Give a link to the search strategy or an example of a search strategy for a specific database if available (including the keywords that will be used in the search strategies).

Alternatively, upload your search strategy to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

Do not make this file publicly available until the review is complete

**18. \* Condition or domain being studied.**

Give a short description of the disease, condition or healthcare domain being studied. This could include health and wellbeing outcomes.

Internalized stigma, also labelled "self-stigma" is defined as per the Livingston and Boyd (2010) paper: Correlates and consequences of internalized stigma for people living with mental illness: A systematic review and meta-analysis. *Social Science & Medicine*, 71(12), 2150-2161.  
doi:10.1016/j.socscimed.2010.09.030

"Internalized stigma as a subjective process, embedded within a socio-cultural context which may be characterised by negative feelings (about self), maladaptive behavior, identity transformation, or stereotype endorsement resulting from an individual's experiences, perceptions or anticipation of negative social reactions on the basis of their mental illness" and offending history.  
This review aims to study health and wellbeing outcomes impacted by or related to internalized stigma as defined above.

### 19. \* Participants/population.

Give summary criteria for the participants or populations being studied by the review. The preferred format includes details of both inclusion and exclusion criteria.

**Adults** (age 18+) in contact with forensic services who experience mental illness.

**Exclusion:**

Individuals with a sole diagnosis of dementia, learning disability, cognitive impairment, brain injury or substance-related disorder.

### 20. \* Intervention(s), exposure(s).

Give full and clear descriptions or definitions of the nature of the interventions or the exposures to be reviewed.

Any intervention or exposure will be reviewed if compared with a measure of internalized stigma.

### 21. \* Comparator(s)/control.

Where relevant, give details of the alternatives against which the main subject/topic of the review will be compared (e.g. another intervention or a non-exposed control group). The preferred format includes details of both inclusion and exclusion criteria.

Not applicable.

### 22. \* Types of study to be included.

Give details of the types of study (study designs) eligible for inclusion in the review. If there are no restrictions on the types of study design eligible for inclusion, or certain study types are excluded, this should be stated. The preferred format includes details of both inclusion and exclusion criteria.

**Editorial commentaries, only where full articles and data are accessible.**

**Quantitative research.**

Papers with full English-language text retrievable through contacting the author(s), NHS or University of Edinburgh resources.

### 23. Context.

Give summary details of the setting and other relevant characteristics which help define the inclusion or exclusion criteria.

**Forensic services:** forensic mental health community and inpatient services, prisons, criminal justice and correctional facilities.

**Mental illness:** DSM-5 / ICD-10 diagnosable conditions (with exclusions) and/or as deemed clinically relevant / defined as such by the research author(s) and/or highlighted in the forensic MH matrix. Includes people deemed 'forensic psychiatric/mental health patients'.

**24. \* Primary outcome(s).**

Give the pre-specified primary (most important) outcomes of the review, including details of how the outcome is defined and measured and when these measurement are made, if these are part of the review inclusion criteria.

Quantitative data, based on scales that measure internalized stigma.

**Timing and effect measures**

**25. \* Secondary outcome(s).**

List the pre-specified secondary (additional) outcomes of the review, with a similar level of detail to that required for primary outcomes. Where there are no secondary outcomes please state 'None' or 'Not applicable' as appropriate to the review

At least one other variable where its statistical relationship or association with internalized stigma is analysed and reported.

**Timing and effect measures**

**26. Data extraction (selection and coding).**

Give the procedure for selecting studies for the review and extracting data, including the number of researchers involved and how discrepancies will be resolved. List the data to be extracted.

**27. \* Risk of bias (quality) assessment.**

State whether and how risk of bias will be assessed (including the number of researchers involved and how discrepancies will be resolved), how the quality of individual studies will be assessed, and whether and how this will influence the planned synthesis.

Risk of bias (quality) assessment will be assessed using a custom-made tool based on the following: NICE quality tool for quantitative studies (intervention and correlations and associations), Cochrane risk of bias Risk of Bias (Quality) for Research Dissemination (CRD) guidelines and co-rated by the second author. Conflicts will be resolved by discussion.

This process will not influence inclusion in data synthesis, unless incorrect data or missing data is identified.

**28. \* Strategy for data synthesis.**

Give the planned general approach to synthesis, e.g. whether aggregate or individual participant data will be used and whether a quantitative or narrative (descriptive) synthesis is planned. It is acceptable to state that a quantitative synthesis will be used if the included studies are sufficiently homogenous.

A descriptive synthesis of data is planned, unless studies are sufficiently homogenous, then a quantitative synthesis will be undertaken.

**29. \* Analysis of subgroups or subsets.**

Give details of any plans for the separate presentation, exploration or analysis of different types of participants (e.g. by age, disease status, ethnicity, socioeconomic status, presence or absence of co-morbidities); different types of intervention (e.g. drug dose, presence or absence of particular components of intervention); different settings (e.g. country, acute or primary care sector, professional or family care); or different types of study (e.g. randomised or non-randomised).

Different types of participants and interventions may be presented and analysed should these factors be correlated with internalized stigma and study methods and measures homogeneous.

No plan is made to differentiate between different types of study, i.e. randomised or non-randomised.

**30. \* Type and method of review.**

Select the type of review and the review method from the lists below. Select the health area(s) of interest for your review.

**Type of review**

Cost effectiveness

No

Diagnostic

No

Epidemiologic

No

Individual patient data (IPD) meta-analysis

No

Intervention

No

Meta-analysis

No

Methodology

No

Network meta-analysis

No

Pre-clinical

No

Prevention

No

Prognostic

No

Prospective meta-analysis (PMA)

No

Qualitative synthesis

No

Review of reviews

No

Service delivery

No

Systematic review

Yes

Other

No

**Health area of the review**

Alcohol/substance misuse/abuse

No

Blood and immune system

No

Cancer

No

Cardiovascular

**PROSPERO**  
International prospective register of systematic reviews

No  
Care of the elderly  
No  
Child health  
No  
Complementary therapies  
No  
Crime and justice  
Yes  
Dental  
No  
Digestive system  
No  
Ear, nose and throat  
No  
Education  
No  
Endocrine and metabolic disorders  
No  
Eye disorders  
No  
General interest  
No  
Genetics  
No  
Health inequalities/health equity  
Yes  
Infections and infestations  
No  
International development  
No  
Mental health and behavioural conditions  
Yes  
Musculoskeletal  
No  
Neurological  
No  
Nursing  
No  
Obstetrics and gynaecology  
No  
Oral health  
No  
Palliative care  
No  
Perioperative care  
No  
Physiotherapy  
No  
Pregnancy and childbirth  
No

**PROSPERO**  
**International prospective register of systematic reviews**

Public health (including social determinants of health)  
No

Rehabilitation  
Yes

Respiratory disorders  
No

Service delivery  
No

Skin disorders  
No

Social care  
No

Surgery  
No

Tropical Medicine  
No

Urological  
No

Wounds, injuries and accidents  
No

Violence and abuse  
No

**31. Language.**

Select each language individually to add it to the list below, use the bin icon to remove any added in error.

There is an English language summary.

**32. Country.**

Select the country in which the review is being carried out from the drop down list. For multi-national collaborations select all the countries involved.

Scotland

**33. Other registration details.**

Give the name of any organisation where the systematic review title or protocol is registered (such as with The Campbell Collaboration, or The Joanna Briggs Institute) together with any unique identification number assigned. (N.B. Registration details for Cochrane protocols will be automatically entered). If extracted data will be stored and made available through a repository such as the Systematic Review Data Repository (SRDR), details and a link should be included here. If none, leave blank.

**34. Reference and/or URL for published protocol.**

Give the citation and link for the published protocol, if there is one

Give the link to the published protocol.

Alternatively, upload your published protocol to CRD in pdf format. Please note that by doing so you are consenting to the file being made publicly accessible.

**No I do not make this file publicly available until the review is complete**

Please note that the information required in the PROSPERO registration form must be completed in full even if access to a protocol is given.

### 35. Dissemination plans.

Give brief details of plans for communicating essential messages from the review to the appropriate audiences.

### Do you intend to publish the review on completion?

Yes

### 36. Keywords.

Give words or phrases that best describe the review. Separate keywords with a semicolon or new line. Keywords will help users find the review in the Register (the words do not appear in the public record but are included in searches). Be as specific and precise as possible. Avoid acronyms and abbreviations unless these are in wide use.

stigma; mental health; forensic; systematic review; psychology

### 37. Details of any existing review of the same topic by the same authors.

Give details of earlier versions of the systematic review if an update of an existing review is being registered, including full bibliographic reference if possible.

### 38. \* Current review status.

Review status should be updated when the review is completed and when it is published.  
Please provide anticipated publication date

Review\_Ongoing

### 39. Any additional information.

Provide any other information the review team feel is relevant to the registration of the review.

### 40. Details of final report/publication(s).

This field should be left empty until details of the completed review are available.

Give the link to the published review.

## Appendix C- Excluded Articles

### Systematic Review: Excluded Full-text Articles

Study Details	Reason(s) for Exclusion
Absalom-Hornby et al (2012) Family intervention using a web camera (e-FFI) within forensic services: A case study and feasibility study	Measures stigma family felt towards patient, not internalised stigma
Adewuya et al (2009) Group psychoeducation for long-term offender patients with schizophrenia: An exploratory randomised controlled trial	Measures perceived stigma- not internalised stigma
Ajdukovic (1990) Psychosocial climate in correctional institutions: Which attributes describe it?	Environmental measure development only
Arabaci (2015) Social functionality and internalised stigmatization levels of forensic psychiatry patients	No English-language full-text available
Arsenault (2010) The stigmatization of mental illness and drug addiction among the criminally involved	Measures stigma felt towards others, not internalised stigma
Assari et al (2018) Discrimination Fully Mediates the Effects of Incarceration History on Depressive Symptoms and Psychological Distress Among African American Men	No measure of internalised stigma
Bell (2000) An evaluation of the forensic support program of Allegheny County	No measure of internalised stigma
Benn (2007) Measures of mentalizing in adults with a diagnosis of schizophrenia: a review of reliability and validity and an empirical test of mentalizing in violent and sexual offending maximum secure hospital samples	No full-text available
Bentley (2017) Incarcerated Women's Experiences and Beliefs About Psychotropic Medication: An Empirical Study	No measure of internalised stigma
Bereswill (2004) Inside-Out: Resocialisation from Prison as a Biographical Process. A Longitudinal Approach to the Psychodynamics of Imprisonment	Qualitative, descriptive, case studies
Blagden et al (2016) "They Treat Us Like Human Beings"--Experiencing a Therapeutic Sex Offenders Prison: Impact on Prisoners and Staff and Implications for Treatment.	No measure of self-stigma

Bogojevic (2012) Possible consequences of insight in schizophrenia	No full-text available
Bogojevic (2011) Suicidality during the implementation of security measure of compulsory psychiatric treatment	No full-text available
Brigitta (2010) Relationship between schizophrenia and criminal behavior	No full-text available
Cai (2004) Identification of grades division to diminished criminal responsibility in mental disorder offender	No English-language full-text available
Caver (2018) A critical examination of the general strain theory: The application of discrimination as a strain and its relationship to criminal behavior and mental health in an African American sample	No measure of internalised stigma
Cechniki (2007) The stigma of mental illness: Anticipation and experiencing	Non-forensic psychiatric population
Chaimowitz (2012) The treatment of mental illness in correctional settings	Descriptive paper
Cherney (2016) Finding and Keeping a Job: The Value and Meaning of Employment for Parolees	Qualitative study
de Domenico (2018) Mental Health and Stigma Challenges of Offenders Reintegrating into the Community	Measures stigma felt towards offenders, not internalised stigma
de Farias (2014) Stigma diagnosis and de-institutionalization of the mentally ill criminal: A case study	Narrative case-study design
de Jong (1992) Factors associated with recidivism in a criminal population	No measure of internalised stigma
Dickens (2011) Labelling people who are resident in a secure forensic mental health service: user views	No measure of internalised stigma
Dirks-Linhorst (2013) An Analysis of Missouri's Insanity Acquittee Population, 1980-2009: Differences Within African American Insanity Acquittees	No measure of internalised stigma
Evans (2006) Locked up, then locked out: women coming out of prison	Descriptive paper
Fong et al (2010) Factors influencing inpatient duration among insanity acquittees in a Malaysian mental institution	No measure of internalised stigma
Fontana (1985) Interpersonal Competence and the community adjustment of mentally ill offenders (forensic psychology, criminals, not guilty by reason of insanity, prediction)	No full-text available
Fruehwald et al (1998) The relevance of self-concepts discriminating in long-term incarcerated sex offenders	No measure of internalised stigma

Fung et al (2007) Measuring self-stigma of mental illness in China and its implications for recovery	Non-forensic psychiatric population
Garner (1993) Challenges in rehabilitation of mentally disordered offenders	Descriptive paper
Gee et al (2005) Keeping the Music Alive: Using the "Grief and Hope Box" with Adult Offenders with Co-Occurring Mental Health and Substance Use Issues	No measure of internalised stigma
Gove and Fain (1973) The stigma of mental hospitalization. An attempt to evaluate its consequences	Non-forensic psychiatric population
Gran (2014) Peer relationships within the recovery journey: perspectives of forensic dual diagnosis clients	Stigma measured qualitatively
Haapasalo (2000) Childhood maltreatment, behavior problems and adult psychiatric disorders: A trauma and attachment theory perspective	No English-language full-text available
Hartwell (2003) Prison, Hospital or Community: Community Re-Entry and Mentally Ill Offenders	No measure of internalised stigma
Hartwell et al (2010) Emerging Adults With Psychiatric Disabilities Involved With the Criminal Justice System	No measure of internalised stigma
Hemphill (2009) The impact of traumatic experiences on subsequent mental health functioning among male sex offenders and male victims of physical and sexual abuse	No measure of internalised stigma
Herbert et al (2015) Homelessness and Housing Insecurity Among Former Prisoners	No measure of internalised stigma
Hutchinson (2008) Promoting social inclusion for users of forensic services	Descriptive paper
Jahnke et al (2015) Stigma-Related Stress and Its Correlates Among Men with Pedophilic Sexual Interests	No MH noted or measure of internalised stigma
Jones (2017) An investigation into the feasibility of psychological interventions for managing the symptoms of trauma and insomnia for women in prison	Stigma measured qualitatively
Kabanov (2004) Stigma, compliance, and quality of life in psychiatric practice (in connection with the objectives of rehabilitation)	Descriptive only
Kalichman (1990) A cluster analytically derived typology of incarcerated rapists based on the MMPI	No measure of internalised stigma

Kelly (2005) Structural violence and schizophrenia	Descriptive only
Krauss (1989) When stigma screams	Editorial- descriptive only
Krupa (1998) An investigation of the relationship between substance abuse and physical and sexual abuse among incarcerated special treatment center adult males	Descriptive only
Lang (2015) Exploring the development and impact of vocational and real work opportunities in a medium secure environment...	Conference proceedings- no full-text available
Leong and Silva (1995) A psychiatric-legal analysis of psychotic criminal defendants charged with murder	No measure of internalised stigma
Levenson et al (2017) Obstacles to Help-Seeking for Sexual Offenders: Implications for Prevention of Sexual Abuse	Stigma measured qualitatively
Livingston (2010) Experiences of stigma and compulsory treatment in the forensic and civil mental health systems of British Columbia	Thesis with results published in another paper
Maercker et al (2013) Course of trauma sequelae in ex-political prisoners in the GDR: A 15-year follow-up study	No English-language full-text available
Margetic (2008) Perception of stigmatization in forensic patients with schizophrenia	No measure of internalised stigma
Matsumoto (2005) Characteristics of self-cutters among male inmates: Association with bulimia and dissociation	No measure of internalised stigma
McKeithen-Franks (1998) The commitment of mentally ill offenders to a forensic psychiatric facility	No measure of internalised stigma
Meyer et al (2014) Why Do Some Jail Inmates Not Engage in Treatment and Services?	No measure of internalised stigma
Meyer (2004) The effects of belonging to the criminal community on inmates' psychological health	No measure of internalised stigma
Mezey et al (2015) Finding a voice - the feasibility and impact of setting up a community choir in a forensic secure setting	Qualitative study
Mezey et al (2016) Stigma and discrimination in mentally disordered offender patients - a comparison with a non-forensic population	No measure of internalised stigma

Moore (2016) A longitudinal model of internalised stigma, coping, and post-release adjustment in criminal offenders	Non-MH population
Moore et al (2016) The Effect of Stigma on Criminal Offenders' Functioning: A Longitudinal Mediational Model	No measure of internalised stigma
Moore and Tagney (2017) Managing the Concealable Stigma of Criminal Justice System Involvement: A Longitudinal Examination of Anticipated Stigma, Social Withdrawal, and Post-Release Adjustment	No measure of internalised stigma
Murakami et al (1998) Predictability of the criminal responsibility of schizophrenics	No full-text available
Nicholson (1978) Discriminators of differences in recidivistic behaviors	
Panton (1979) MMPI profiles associated with outcomes of intensive psychotherapeutic counseling with youthful first offender prison inmates	No full-text available
Panton (1979) MMPI profile configurations associated with incestuous and non-incestuous child molesting	No measure of internalised stigma
Peterson (2017) Creating community and shattering stigma: Collaborative arts interventions for the forensic population	Descriptive paper
Phelan et al (2010) Effectiveness and outcomes of assisted outpatient treatment in New York State	Perceived rather than internalised stigma measured
Phillips (2005) Risk Assessment in Offenders with Mental Disorders: Relative Efficacy of Personal Demographic, Criminal History, and Criminal Variables	No measure of internalised stigma
Redoon et al (1999) Therapeutic factors in group treatment evaluated by sex offenders: A consumers' report	No measure of internalised stigma
Roskes (1999) A model program for the treatment of mentally ill offenders in the community	Descriptive paper
Rosler (2010) Does stigma impair treatment response and rehabilitation in schizophrenia? The "contribution" of mental health professionals	Descriptive- book chapter
Shaw & Humber (2010) Suicide and self-injury in offenders	Descriptive- book chapter
Simon et al (2017) Caregivers' abuse stigmatization and their views of mental health treatment following child sexual abuse	Measures stigma family felt towards another, not internalised-stigma

Sultan and Long (1988) Treatment of the sexually/physically abused female inmate: Evaluation of an intensive short-term intervention program	No measure of internalised stigma
Tang and Wang (2007) Relation factors of the criminal responsibility in the offenders with mental disorders by the discriminatory analysis	No English-language full-text available
Toyoki & Brown (2014) Stigma, identity and power: Managing stigmatized identities through discourse	Qualitative study
Tschopp et al (2007) Employment barriers and strategies for individuals with psychiatric disabilities and criminal histories	Qualitative study with no measure of internalised stigma
Uchino (2012) Psychoeducation may reduce self-stigma of people with schizophrenia and schizoaffective disorder	Non-forensic population
Vandamme (2004) Temperament and Character Inventory in Homicidal, Nonaddicted Paranoid Schizophrenic Patients: A Preliminary Study	No measure of internalised stigma
Wall et al (2015) Identifying Overreporting in a Correctional Setting: Utility of the MMPI-2 Restructured Form Validity Scales	No measure of internalised stigma
West et al (2014) Triple Stigma of Forensic Psychiatric Patients: Mental Illness, Race, and Criminal History	Descriptive paper
West (2015) Triple Stigma in Forensic Psychiatric Patients: Mental Illness, Race, and Criminality	Thesis with results published in another paper
Williams et al (2001) Attitudes of Male Prisoners toward Seeking Professional Psychological Help	No measure of internalised stigma

## Appendix D- Quality Assessment

### Systematic Review: Details of quality assessment tool

Study Details	Was the study design appropriate to the research question?	Was the eligible population representative of the source population or area?	Allocation to intervention/ exposure (or comparison) group. How was selection bias minimised?	Were participants/ researchers blind to exposure and comparison and both delivered adequately?	How well were likely confounding factors identified and controlled for?	Was the choice(s) of stigma measure(s) appropriate, reliable and valid?	Were the choice(s) of outcome measure(s) appropriate, reliable and valid?	Were there significant issues with attrition to bias outcomes or comparisons?	Was the study sufficiently powered to detect an effect (if one exists)?	Were the analytic methods appropriate?	Were there issues with the reporting of results such that bias towards certain findings was apparent?
	Was recruitment appropriate? Were the inclusion/exclusion criteria clear & appropriate? Was the sample generalisable?	Was allocation truly random (++) or pseudo-random (+), e.g. consecutive admissions?	Could quality have been influenced by those delivering or participating in the intervention?	Were there likely to be confounding factors not considered or appropriately adjusted for? Was this sufficient to cause important bias?	Did the tools measure stigma? Were they validated or assessed for content or inter/intra-rater reliability?	Did the outcomes measure what they said they would? Were they validated or assessed for content or inter/intra-rater reliability?	Were drop-outs between baseline and follow-up acceptably low (<20%)? Did the proportion drop-out differ by group?	Was the power calculable such that there was 20% or less chance of a Type II error?	Were important differences adjusted for? Were sub-group analyses performed pre-specified?	Were there biases towards only significant results? Were there unreported results of relevance?	

Assessment scoring scale (from NICE quality assessment tool):

- ++ For that particular aspect of study design, the study has been designed or conducted in such a way as to minimise the risk of bias
- + Either the answer to the question is not clear from the way the study is reported, or that the study may not have addressed all potential sources of bias for that aspect design
- Aspect of the study design in which significant sources of bias may persist

**NR:** not reported, **NA:** not applicable

# Appendix E- Protocol

Empirical Study: Protocol submitted to and approved by the Forensic Network

Jane-Louise Jackson

Research Protocol

## FNRSIG Research Proposal (for shared approval) / Study Protocol

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### 1. Applicant Information

**Contact Details:** Ms Jane-Louise Jackson (Principal Investigator)  
NHS Forth Valley -Forensic Community Mental Health Services  
c/o Dr Clare Neil  
Falkirk Community Hospital  
Westburn Avenue  
Falkirk, FK1 5QE

[s1580004@sms.ed.ac.uk](mailto:s1580004@sms.ed.ac.uk) (University of Edinburgh email)  
[jane-louise.jackson@nhs.net](mailto:jane-louise.jackson@nhs.net) (NHS email)

**Current Post(s):** Trainee Clinical Psychologist, NHS Forth Valley  
DClinPsychol Student, University of Edinburgh

**Qualifications:** Graduate Diploma (conversion) Psychology with distinction  
(awarded November 2012 - Glasgow Caledonian University)

BSc (Hons) Physics 2:1  
(awarded June 2006 - University of Dundee)

**Research Experience:** Service evaluation of provision of psychological therapies in Acute  
Hospital Old-Age Psychiatric Liaison Team.  
Assistant Psychologist (2014-2015), NHS GG&C

DCAQ Audit of Adult Psychological Therapies Teams.  
Assistant Psychologist (2013-2014) NHS Lanarkshire.

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Graduate Diploma (conversion) Psychology-  
Empirical Project (2011-2012) Glasgow Caledonian University.

**Relevant Training:** PMVA Breakaway training: ½ day NHS Forth Valley, 2015

PMVA Breakaway training: 2day NHS GG&C, 2014.

Research- including qualitative methods, ethics and good practice.  
University of Edinburgh, 2015/2016 & 2016/2017.

## 2. Proposed Project Information

**Proposed Title:** What promotes wellbeing of older-adults in secure forensic settings?  
Perceptions from older-adult forensic inpatients and staff.

**Proposed Starting and Completion Dates:** July 2017-August 2018

**REC / R&D Approval Requirements, and Status of Application Processes:**

Approval Required	Status
IRAS (REC, NHS/HSC R&D and SSI)	In progress (submission approx. June 2017)
University of Edinburgh Ethics	In progress (submission approx. June 2017)
Forensic Network Approval	In progress (submission approx. June 2017)
Caldicott (NRS)	In progress

**Identified Site Contact for each Forensic Network site:**

Site	Board	Contact
Bellsdyke Hospital	NHS Forth Valley	Dr Clare Neil
The State Hospital	State Hospitals Board	Dr Amelia Cooper
The Orchard Clinic	NHS Lothian	Dr Louise Tansey
Rowanbank	NHS Greater Glasgow and Clyde (GG&C)	Dr Emma Drysdale
Leverndale	“	“
Beckford Lodge	NHS Lanarkshire	Dr Fiona Mair
Royal Cornhill	NHS Grampian	Dr Karen Allan

**Line Manager, Clinical or Academic Supervisor approval signatures:**

Dr Clare Neil (Clinical/Field Supervisor) \_\_\_\_\_

Dr Ethel Quayle (Academic Supervisor) \_\_\_\_\_

## 3. Introduction

### 3.1 Wellbeing of Older People

The World Health Organisation (2015) projects the average life expectancy of people living in Europe to reach 80 years by 2050 and with both the population and proportion of older people increasing, public health research and policies on ageing cannot be ignored. Research interest with older people has grown in response to the ageing population, however WHO

report that barriers remain, based on stereotypical views about ageing, including being a burden on services (World Health Organisation, 2015).

In healthcare settings, it is important to note that staff may hold stigmatising attitudes towards patients, which may in turn influence their interactions (Lammie, Harrison, Macmahon, & Knifton, 2010). This is particularly relevant when considering staff attitudes about older-adult forensic inpatients due to the potential for discrimination according to age, mental ill-health and forensic history (Slade et al., 2014). In general, there is a higher prevalence of physical health conditions among older people, in addition to experiencing life-stage transitions such as retirement/change of role, loss and bereavement. Research has suggested that older people in prisons may be excluded from activities and become socially isolated as a result of their age, with resources typically directed towards groups who are seen to have more behavioural problems (Fazel, Hope, Donnell, & Jacoby, 2001; Hayes, Burns, Turnbull, & Shaw, 2012; O'Hara et al., 2016). Scotland's 2012-2015 Mental Health Strategy reported that social isolation and loss are two of the main risk factors for mental ill-health and can lead to hopelessness and depression (Scottish Government, 2012).

The specific experiences of older people mentioned above are acknowledged in the Acceptance and Commitment Therapy (ACT) model (Hayes, Luoma, Bond, Masuda, & Lillis, 2006), which suggests four key areas in life: work/learning, leisure, personal growth/health and relationships. This model suggests that understanding what you value in each area (e.g. family relationships) and living and life in accordance to those values (e.g. being a good Father) promotes wellbeing (Harris, 2008). It is clear, therefore, that understanding patients' values could aid service development and the resource allocation to enable services to promote wellbeing.

### 3.2 The Recovery Approach and Forensic Settings

Scotland's 2012-2015 Mental Health Strategy outlined commitments to a recovery-based, holistic approach to mental health care integrating five elements: connectedness, hope, identity, meaning and environment (CHIME) (Scottish Government, 2012). Recovery in this sense has become an internationally recognised and advocated philosophy underpinning mental health policy in Scotland (Cleary & Dowling, 2009; Slade *et al.*, 2014; Tilley & Cowan, 2011).

Mental health policy in Scotland was developed based on recovery defined as "...a way of living a satisfactory, hopeful and contributing life even with the limitations caused by illness." (Anthony, 1993, p. 15; Tilley & Cowan, 2011). Some healthcare workers share concerns about effective integration, which would require a commitment to recovery-oriented services (involving time for training and implementation) by all staff and management (Slade et al., 2014). Staff are invaluable to the process of imbedding a culture of recovery and forensic inpatient settings present an opportunity for staff to promote this ideology by providing consistent meaningful engagements with patients to model pro-social, caring, functional and collaborative relationships based on trust (Salzmann-Erikson, Rydlo, & Wiklund Gustin, 2016).

The development and integration of the Good Lives Model of offender rehabilitation has contributed to a more holistic culture of care (Barnao, Ward, & Robertson, 2016). This model fits well with the recovery approach and the ACT model by supporting people to safely explore values including relatedness, community and agency (Simpson & Penney, 2011). Furthermore, the recovery approach seems to reflect the longstanding gold standard of healthcare for older people, particularly as it promotes living well with illness (Hilton & Hulman, 2010).

### 3.3 Research and clinical practice

Research with older forensic inpatients in high security hospitals highlighted a lack of understanding of their needs (Yorston & Taylor, 2009). The current evidence base is further limited by a lack of agreement on the age at which someone with a forensic background should be considered 'old' (Kakoullis, Le Mesurier, & Kingston, 2010). Many researchers have lowered the age cut-off for the forensic population (from 65 years to 50-59 years) due to so-called 'accelerated ageing' from a combination of lifestyle factors, mental health, substance misuse, violence, trauma and a lack of preventative healthcare (Baidawi, 2016; Baidawi et al., 2011; Ginn, 2012; Williams, Ahalt, & Greifinger, 2014). Older-adults will be defined in this study as people aged 55 years and over, which considers the evidence base for premature ageing amongst an offending population and supports a preventative approach to healthcare, including preparation for later life (Cooney & Braggins, 2010). In addition, this is in line with a current NHS study proposed to look at the psychiatric needs of older forensic inpatients, which uses 55+ based on the authors' clinical experience and past research (Lightbody, Gow, & Gibb, 2010; McLeod, Yorston, & Gibb, 2008).

Research suggested that patients might view the recovery approach as 'top down', without a grounding in individual values and needs (Tilley & Asquith, 2008). How such an approach is implemented is key to its integration in healthcare settings. It is suggested here that the research process in itself can nurture a sense of agency and the study's results emerging from data (from qualitative interviews with patients) provides patients an opportunity to directly influence service provision and care culture. Furthermore, the impact of professional relationships should not be minimised, with good clinical practice involving time spent with patients to identify, explore and develop their strengths, challenge antisocial/ maladaptive beliefs and behaviours and learn skills for living well in the future (Drennan & Alred, 2012). It seems clear, therefore, that the exploratory research proposed herein should involve staff and patients, so that results can be used to impact healthcare settings as a whole (i.e., staff, patients and care culture through relationships) (Salzmann-Erikson et al., 2016).

## 4. Aims

This study aims to explore what promotes wellbeing in older-adult forensic inpatients. By interviewing older-adult forensic inpatients and staff, this study will explore and compare perceived values of older-adult forensic inpatients. Comparisons will also be drawn between study results and Good Lives Model to see how elements of the recovery approach (e.g. ability to live well despite limitations of mental illness) fits with what is important for this population.

The principal question for older people in forensic mental health inpatient setting is "What helps you feel good in yourself?"

Follow-up questions may include (for patients):

"How to those things/people etc. help you?"

"What gets in the way those things?"

"Can you give me an example of when something happened here that made you feel good in yourself?"

"How have these things changed since you came to this ward?"

"As we all get older, what is important to us can change- what do you think will be important to you as you get older?"

"What sort of person would you like to be remembered as?"

The principal question for staff working in forensic mental health inpatient setting is "What do you think is important to older-adult forensic inpatients?"

Follow-up questions may include (for staff):

“Can you give me an example of when something happened here that you think was good for the wellbeing of the older-adult forensic inpatients?”

“How do you think what matters to an older-adult forensic inpatient changes from what mattered to them on admission?”

“As we all get older, what is important to us can change- what do you think will be important to inpatients in this setting as they age, in terms of their wellbeing?”

“What about this setting helps and/or hinders older-adult forensic inpatients from living a life that helps them feel good in themselves?”

Other prompts may be around ACT values, e.g. environment, relationships, work, leisure.

During ongoing qualitative data analysis, the following secondary research questions will be addressed: How do staff and patient views fit with the recovery model of service provision? How do staff and patient views compare?

## 5. Plan of Investigation

### 5.1 Design

A qualitative, exploratory study using Grounded Theory Methodology (GTM) (Charmaz, 2014). This is suggested as a useful research method when exploring a topic or population that has not previously been explored, or to develop a deeper understanding of a phenomenon. It is appropriate therefore to use this approach to explore the values of older people in forensic inpatient settings, as this particular group has not been consulted previously. In addition, the GTM approach is helpful in exploring the meaning people attach to their experiences and analyse relationships between emerging themes and concepts.

### 5.2 Recruitment, Population and Sampling

This study aims to recruit 10 patient participants and 10 staff participants, for participation in individual patient interviews and staff focus groups. These numbers are hoped to be gained by initially targeting only the State Hospital and Bellsdyke Hospital (NHS Forth Valley). The named site contacts (see section 2) will be asked to facilitate communication between the PI and medical records/administration to gain the overall number of staff and patients (over 55 years old) at each site, as well as contact details for the Responsible Medical Officers (RMO). Following this, the PI will contact RMOs (from the State Hospital and Bellsdyke only in the first instance) to gain a potential sample of participants based on those identified as being older than 55 years and the RMOs knowledge of their capacity and suitability according to the study's eligibility criteria. At this stage, Jamie Pitcairn (R&D Manager, The State Hospital) will be asked to provide demographic information, where possible, from the most recent patient census. This is hoped to provide information such that the PI can approach patients with a length of stay over 2 years, such that they might be suggested as experiencing some of the aforementioned forensic ageing process. In addition, by targeting recruitment to capture a range of patients with variable admission lengths, this study hopes to represent as wide a population as possible, within these settings. Staff management will be contacted and asked how the PI should best approach staff recruitment in their site, and to help identify suitable staff participants where possible.

Communication with the RMO and staff managers will aim to minimise the time burden for staff and patients and a mutually suitable time and venue will be agreed, considering resource and clinical commitments. For staff participation, it is intended that the PI will liaise with management and offer to attend sites during CPD/education sessions. For patients, the PI will

discuss with the RMO suitable times per individual, considering their other activities and commitments.

Purposive sampling will be carried out according to the following eligibility criteria:

#### Patients

- Forensic mental health inpatients of low, medium and high secure settings
- Aged 55 years old or older
- English speakers
- Have capacity to give informed consent

#### Staff

- Staff who have regular clinical contact with forensic mental health inpatients (excludes domestic staff and students)
- English speakers

By nature of the GTM approach, sampling becomes theoretical during the data collection period, as themes begin to emerge from the data. This means that the eligibility criteria may change and the interview questions amended during the data collection/analysis period. This will allow exploration of the impact of variables such as environment (i.e. inpatient setting security level) and access to services (e.g. psychological therapy) on participant experience. Theoretical sampling can narrow the population from which to recruit, which may bring recruitment issues to this study, which is already targeting a minority group within forensic services. Therefore, it is important that this study can access a number of sites within the Forensic Network if required, and approval for a multi-site study is sought.

All participants will be provided with an information sheet and be given the opportunity to ask questions before providing their written informed consent. Participants will be told they are free to withdraw from the study, without penalty, up to the data analysis stage, where their anonymised data will form part of the study's results.

### 5.3 Data Collection and Analysis

Interviews and staff focus groups are expected to last up to an hour, although this may vary between individual participants (Glaser & Strauss, 1967; Strauss & Corbin, 1998). The researcher will be open-minded to what may come up in interviews, and lead with only one preconceived question to begin the interview, followed by prompts and exploratory questions to gain a fuller understanding of participants' experiences.

Data collection will comprise qualitative semi-structured individual interviews and staff focus groups conducted according to the Grounded Theory Methodology (GTM) approach.

Concurrent analysis will be managed using Dedoose software (<http://www.dedoose.com/>) with anonymised transcriptions analysed according to GTM, including:

- Line by line data coding to allow detailed descriptive categories to emerge
- Use of memos and diagrams to analyse relationships between descriptive categories
- Drawing together of similar emergent categories into higher-level analytic categories
- Support from colleagues for cross-coding
- Use of emerging themes (removing confidential information) to construct subsequent interview schedules (for validation or to further understanding of themes and relationships)
- Integrating categories from staff and patient interview analyses
- Formulation of theoretical model drawn from themes
- Feedback/analysis of theoretical model's fit with participant views in follow-up interviews where possible

Concurrent data collection and analysis will continue until no new concepts arise and the relationships between concepts are understood (i.e. data saturation), or earlier, if limited by participant recruitment.

Patient demographic information will be collected based on individual self-report (age, gender, length of current admission and mental health diagnosis), as well as via the inpatient census (information via Jamie Pitcairn at the State Hospital). Staff will be asked for their age, gender, profession and number of years' experience in a forensic setting. The impact on the results of this study from these variables will be managed via exploration in interviews and ongoing development of the interview schedule. Due to predicted low numbers of participants in this study, it is not expected that the PI will be able to draw comparisons between different demographic groups within patient and staff samples (i.e. age groups, different diagnostic categories). Rather, this information will be used to place the study's results in context.

**5.4 Dissemination**

All participants will have the opportunity to have a follow-up interview face to face to validate the emergent theoretical model

The PI will present research findings to staff and patients at education/CPD session in NHS Forth Valley (Bellsdyke Hospital). In addition, this presentation will be offered to the other study sites, when convenient for participants and subject to the availability of the PI. A brief written report of the study's results will be provided to participating sites for internal circulation.

The results of this study will be written up as a thesis and submitted to the University of Edinburgh as part of the Doctorate in Clinical Psychology. This study will be defended at a viva examination and, following any corrections, be submitted for publication in peer-reviewed journals.

**6. Timetable of Work**

Proposed Study Timetable	Oct 16	Nov 16	Dec 16	Jan 17	Feb 17	Mar 17	Apr 17	May 17	Jun 17	Jul 17	Aug 17	Sep 17	Oct 17	Nov 17	Dec 17	Jan 18	Feb 18	Mar 18	Apr 18	May 18	Jun 18	Jul 18	Aug 18	Sep 18	Oct 18	Nov 18	Dec 18		
University research Proposal	█																												
Write data management p-Plan		█	█																										
Prepare information sheet and consent forms			█	█																									
Prepare interview schedule				█	█																								
Establish links with Psychologists at FN sites					█	█																							
Apply for shared study Forensic Network approval						█	█																						
IRAS application (REC, R&D, SIS)							█	█																					
University of Edinburgh Ethics application								█	█																				
Contact Management and RMOs to discuss recruitment									█	█																			
Recruitment										█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
Data collection											█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
Transcription												█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
Data analysis													█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
Cross-coding														█	█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
Develop theoretical model															█	█	█	█	█	█	█	█	█	█	█	█	█	█	█
Follow-up interviews/groups																													
Draft thesis																													
Thesis submission																													
Viva examination																													
Corrections																													
Write-up results for participants																													
Presentations of findings																													
Submission to peer-reviewed journals																													

**7. Purpose and Potential for Implementation of Results**

This study will be the first to specifically explore the values and wellbeing of the older adult forensic inpatient population in Scotland using a Grounded Theory Methodology (GTM) approach (Charmaz, 2014; Glaser & Strauss, 1967; Strauss & Corbin, 1998) to generate a

theoretical model from ongoing qualitative data collection and analysis. This will contribute to the growing evidence base surrounding the recovery approach to service provision.

Developing a rich understanding of the values and wellbeing of older-adult forensic inpatients could be used to directly influence policy and service provision. By comparing values with the current recovery approach, inconsistencies and ineffective clinical practice strategies may be highlighted and the culture of care in forensic inpatient settings shaped according to the emerging theoretical model. For example, should this study's results contribute further evidence for recovery approach's strategies for living well with illness, care strategies consistent with these themes could reduce re-admission rates.

#### 8. Information/Data governance procedures

Interviews will be audio recorded using an encrypted digital voice recorder, which will be kept in a locked briefcase (and on the PI's person or in the PI's car boot whilst travelling) unless the PI is in their office, in which case it will be stored within a locked filing cabinet within a locked office in the Forensic Community Mental Health Service (FCMHS) in Falkirk Community Hospital, NHS Forth Valley. All electronic written/audio information and hand written supplementary notes will be stored confidentially according to the NHS Forth Valley and University of Edinburgh data protection policies. In addition, interview and focus group transcripts will be anonymised during transcription and stored separately to demographic information.

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## Appendix F- Ethical Approval

Empirical Study: Favourable Ethics Opinion Letters (Most recent first)

**WoSRES**  
*West of Scotland Research Ethics Service*



Ms Jane-Louise Jackson  
c/o Dr Clare Neil  
Forensic Community Mental Health Service  
Westburn Building  
Falkirk Community Hospital  
Westburn Avenue  
Falkirk  
FK1 5SU

**West of Scotland REC 5**  
West of Scotland Research Ethics Service  
West Glasgow Ambulatory Care Hospital  
Dalnair Street  
Glasgow  
G3 8SJ

Date 07 December 2017

Direct line 0141 232 1809  
E-mail WoSREC5@ggc.scot.nhs.uk

Dear Ms Jackson

**Study title:** What promotes wellbeing of older-adult forensic mental health patients? Perceptions from older-adult forensic inpatients and staff.  
**REC reference:** 17/WS/0161  
**Amendment number:** 1 (REC Ref AM02)  
**Amendment date:** 16 November 2017  
**IRAS project ID:** 223996

The above amendment was reviewed by the Sub-Committee in correspondence.

### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

### Approved documents

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Letters of invitation to participant	2	13 November 2017
Notice of Substantial Amendment (non-CTIMP)	1	16 November 2017
Other [Letter detailing Amendment]		
Other [FV Patient Debrief Sheet]	2	17 November 2017
Other [GGC Patient Debrief Sheet]	2	17 November 2017
Other [TSH Patient Debrief Sheet]	2	17 November 2017
Other [RMO Letter]	2	17 November 2017
Other [FV Staff Debrief Sheet]	2	17 November 2017
Other [GGC Staff Debrief Sheet]	2	17 November 2017
Other [TSH Staff Debrief Sheet]	2	17 November 2017
Participant information sheet (PIS) [FV Patient Information sheet and Consent form]	4	13 November 2017
Participant information sheet (PIS) [GGC Patient Information sheet and Consent form]	2	13 November 2017

Participant information sheet (PIS) [TSH Patient Information sheet and Consent form]	4	13 November 2017
Participant information sheet (PIS) [FV Staff Information sheet and Consent form]	3	13 November 2017
Participant information sheet (PIS) [GGC Staff Information sheet and Consent form]	2	13 November 2017
Participant information sheet (PIS) [TSH Staff Information sheet and Consent form]	3	13 November 2017
Research protocol or project proposal	2	13 November 2017

### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

### Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>17/WS/0161:</b>	<b>Please quote this number on all correspondence</b>
--------------------	---

Yours sincerely



for  
**Dr Stewart Campbell**  
**Chair**

Enclosures: List of names and professions of members who took part in the review

Copy to: Ms Allyson Bailey, NHS Forth Valley  
Mrs Charlotte Smith, University of Edinburgh

### West of Scotland REC 5

### Attendance at Sub-Committee of the REC meeting

#### Committee Members:

<i>Name</i>	<i>Profession</i>	<i>Present</i>	<i>Notes</i>
Mr Hamish Fulford	Lecturer in Mental Health	Yes	
Canon Matt McManus	Parish Priest (Vice-Chair)	Yes	

#### Also in attendance:

<i>Name</i>	<i>Position (or reason for attending)</i>
Mrs Sharon Macgregor	REC Manager

Ms Jane-Louise Jackson  
c/o Dr Clare Neil, Forensic Community Mental  
Health Service  
Westburn Building, Falkirk Community Hospital,  
Westburn Avenue  
Falkirk  
FK1 5SU

**West of Scotland REC 5**  
Research Ethics  
Clinical Research and Development  
West Glasgow Ambulatory Care Hospital  
Dalnair Street  
Glasgow  
G3 8SJ  
(Formerly Yorkhill Childrens Hospital)

Date 07 August 2017  
Direct line 0141 232 1804  
E-mail WoSREC5@ggc.scot.nhs.uk

Dear Ms Jackson

**Study title:** What promotes wellbeing of older-adults in secure forensic settings? Perceptions from older-adult forensic inpatients and staff.  
**REC reference:** 17/WS/0161  
**Amendment number:** AM01 Minor  
**Amendment date:**  
**IRAS project ID:** 223996

*Summary of Minor Amendment: Minor changes to patient and staff PIS, CF and debrief sheet*

Thank you for your letter received 7 August 2017, notifying the Committee of the above amendment.

The Committee does not consider this to be a “substantial amendment” as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require an ethical opinion from the Committee and may be implemented immediately, provided that it does not affect the approval for the research given by the R&D office for the relevant NHS care organisation.

**Documents received**

The documents received were as follows:

Document	Version	Date
Notice of Non Substantial Amendment [Cover Letter]	AM01 Minor	
Other [Patient Debrief GGC]	1	02 August 2017
Other [Staff Debrief GGC]	1	02 August 2017
Participant information sheet (PIS) [Patient Information and Consent form FV]	3	02 August 2017

<i>Document</i>	<i>Version</i>	<i>Date</i>
Participant information sheet (PIS) [Patient Information and Consent form GGC]	1	02 August 2017
Participant information sheet (PIS) [Patient Information and Consent form TSH]	3	02 August 2017
Participant information sheet (PIS) [Staff Information and Consent form GGC]	1	02 August 2017

**Statement of compliance**

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

<b>17/WS/0161:</b>	<b>Please quote this number on all correspondence</b>
--------------------	---

Yours sincerely



**Rose Gallacher**  
**Assistant Administrator**

Copy to: *Ms Allyson Bailey, NHS Forth Valley*  
*Charlotte Smith, University of Edinburgh*

Ms Jane-Louise Jackson  
c/o Dr Clare Neil, Forensic Community Mental  
Health Service  
Westburn Building, Falkirk Community Hospital,  
Westburn Avenue  
Falkirk  
FK1 5SU

**West of Scotland REC 5**  
Research Ethics  
Clinical Research and Development  
West Glasgow Ambulatory Care Hospital  
Dalnair Street  
Glasgow  
G3 8SJ  
(Formerly Yorkhill Childrens Hospital)

Date 31 July 2017  
Direct line 0141 232 1804  
E-mail WoSREC5@ggc.scot.nhs.uk

Dear Ms Jackson

**Study title:** What promotes wellbeing of older-adults in secure forensic settings? Perceptions from older-adult forensic inpatients and staff.  
**REC reference:** 17/WS/0161  
**IRAS project ID:** 223996

Thank you for your e-mail of 31 July 2017. I can confirm the REC has received the documents listed below and that these comply with the approval conditions detailed in our letter dated 21 July 2017

**Documents received**

The documents received were as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Participant information sheet (PIS) [PIS Forth Valley]	2	24 July 2017
Participant information sheet (PIS) [PIS State Hospital]	2	24 July 2017
Participant information sheet (PIS) [PIS Staff Forth Valley]	2	24 July 2017
Participant information sheet (PIS) [PIS Staff State Hospital]	2	24 July 2017
Response to Additional Conditions Met [E-mail]		31 July 2017

**Approved documents**

The final list of approved documentation for the study is therefore as follows:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Edinburgh Insurance]		25 July 2016

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [EL Certificate]		01 August 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [PL Confirmation]		21 July 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [CT Liability]		25 July 2016
GP/consultant information sheets or letters [About the Study]	1	26 June 2017
GP/consultant information sheets or letters [RMO letter]	1	26 June 2017
Participant information sheet (PIS) [Patient Debrief Sheet-Forth Valley]	1	26 June 2017
Participant information sheet (PIS) [Patient Debrief-The State Hospital]	1	26 June 2017
Participant information sheet (PIS) [Staff Debrief-The State Hospital]	1	26 June 2017
Participant information sheet (PIS) [PIS Forth Valley]	2	24 July 2017
Participant information sheet (PIS) [PIS State Hospital]	2	24 July 2017
Participant information sheet (PIS) [PIS Staff Forth Valley]	2	24 July 2017
Participant information sheet (PIS) [PIS Staff State Hospital]	2	24 July 2017
REC Application Form [REC_Form_05072017]		05 July 2017
Research protocol or project proposal [Study Protocol]	1	26 June 2017
Response to Additional Conditions Met [E-mail]		31 July 2017
Summary CV for Chief Investigator (CI) [CI CV]	1	26 June 2017
Summary CV for supervisor (student research) [Academic supervisor CV]		

You should ensure that the sponsor has a copy of the final documentation for the study. It is the sponsor's responsibility to ensure that the documentation is made available to R&D offices at all participating sites.

<b>17/WS/0161</b>	<b>Please quote this number on all correspondence</b>
-------------------	---

Yours sincerely



**Rose Gallacher**  
**Assistant Administrator**

Copy to: *Charlotte Smith, University of Edinburgh*  
*Ms Allyson Bailey, NHS Forth Valley*

Ms Jane-Louise Jackson  
c/o Dr Clare Neil, Forensic Community Mental  
Health Service  
Westburn Building  
Falkirk Community Hospital  
Westburn Avenue  
Falkirk FK1 5SU

**West of Scotland REC 5**  
West of Scotland Research Ethics Service  
West Glasgow Ambulatory Care Hospital  
(former Royal Hospital for Sick Children Yorkhill)  
Dalnair Street  
Glasgow G3 8SJ  
[www.nhs.gov.uk](http://www.nhs.gov.uk)

Date 21<sup>st</sup> July 2017  
Your Ref  
Our Ref  
Direct line 0141 232 1809  
E-mail WOSREC5@ggc.scot.nhs.uk

Dear Ms Jackson

**Study title:** What promotes wellbeing of older-adults in secure forensic settings? Perceptions from older-adult forensic inpatients and staff.  
**REC reference:** 17/WS/0161  
**IRAS project ID:** 223996

The Research Ethics Committee reviewed the above application at the meeting held on 19 July 2017. Thank you for attending to discuss the application.

We plan to publish your research summary wording for the above study on the HRA website, together with your contact details. Publication will be no earlier than three months from the date of this favourable opinion letter. The expectation is that this information will be published for all studies that receive an ethical opinion but should you wish to provide a substitute contact point, wish to make a request to defer, or require further information, please contact [hra.studyregistration@nhs.net](mailto:hra.studyregistration@nhs.net) outlining the reasons for your request. Under very limited circumstances (e.g. for student research which has received an unfavourable opinion), it may be possible to grant an exemption to the publication of the study.

### **Ethical opinion**

The members of the Committee present gave a favourable ethical opinion of the above research on the basis described in the application form, protocol and supporting documentation, subject to the conditions specified below. .

### **Conditions of the favourable opinion**

The REC favourable opinion is subject to the following conditions being met prior to the start of the study.

1. The words "are an inpatient of a secure NHS ward and" should be removed from the "Why have I been invited?" section of the Information Sheet.
2. In the Information Sheet, "RMO" should also be stated in full.
3. In the Consent form, the instruction above the boxes should be changed to "Please initial box".

**You should notify the REC once all conditions have been met (except for site approvals from host organisations) and provide copies of any revised documentation with updated version numbers. Revised documents should be submitted to the REC electronically from IRAS. The REC will acknowledge receipt and provide a final list of the approved documentation for the study, which you can make available to host organisations to facilitate their permission for the study. Failure to provide the final versions to the REC may cause delay in obtaining permissions.**

Management permission must be obtained from each host organisation prior to the start of the study at the site concerned.

Management permission should be sought from all NHS organisations involved in the study in accordance with NHS research governance arrangements. Each NHS organisation must confirm through the signing of agreements and/or other documents that it has given permission for the research to proceed (except where explicitly specified otherwise).

Guidance on applying for HRA Approval (England)/ NHS permission for research is available in the Integrated Research Application System, at [www.hra.nhs.uk](http://www.hra.nhs.uk) or at <http://www.rdforum.nhs.uk>.

Where a NHS organisation's role in the study is limited to identifying and referring potential participants to research sites ("participant identification centre"), guidance should be sought from the R&D office on the information it requires to give permission for this activity.

For non-NHS sites, site management permission should be obtained in accordance with the procedures of the relevant host organisation.

Sponsors are not required to notify the Committee of management permissions from host organisations.

**It is the responsibility of the sponsor to ensure that all the conditions are complied with before the start of the study or its initiation at a particular site (as applicable).**

#### **Ethical review of research sites**

The favourable opinion applies to all NHS sites taking part in the study taking part in the study, subject to management permission being obtained from the NHS/HSC R&D office prior to the start of the study (see "Conditions of the favourable opinion" below).

#### **Summary of discussion at the meeting**

##### **Social or scientific value; scientific design and conduct of the study**

It was not clear what direction the follow-up interviews will take as there was no information on what type of questions will be asked.

*You advised that you would discuss the results of the study with participants and ask whether they agree with the findings.*

The Committee asked whether grounded theory was appropriate for this study.

*You advised that this was the best method as this type of study has not been done before in this group of patients.*

The Chair then asked whether there was potential for this biasing the results as staff may select only participants who they know will give positive feedback.

*You advised that you were aware of this issue.*

**Favourable risk benefit ratio; anticipated benefit/risks for research participants (present and future)**

It was noted that the consideration of risk and benefits to participants and the researcher was evident with steps indicating procedures to reduce risks. The Chair asked whether staff would be present during interviews and whether this would affect what participants said.

*You clarified that you only work one to one with participants and the risk will be assessed by ward staff whether it is safe to be alone with a particular patient.*

**Care and protection of research participants; respect for potential and enrolled participants' welfare and dignity**

It was unclear how long personal information will be stored.

*You advised that this will be kept for the duration of the project.*

**Informed consent process and the adequacy and completeness of participant information**

Although patients may know what an "RMO" is, this should be stated in full in the Information Sheet.

It is not necessary to include the location of potential participants in the Information Sheet as this information is not required.

The Committee advised that it may be more appropriate that the boxes in the Consent form are initialled, rather than ticked, in this study.

*You agreed to make these changes to the documentation.*

**Other ethical issues were raised and resolved in preliminary discussion before your attendance at the meeting.**

**Recruitment arrangements and access to health information, and fair participant selection**

It was noted in A31 that participants will be given no less than 24 hours to consider whether they wish to take part in the study. However, it was also noted that the researcher would try to make contact with the Responsible Medical Officer within one week and elsewhere in the submission it was noted that at least 48 hours would be given. No further issues were raised.

Please contact the REC Manager if you feel that the above summary is not an accurate reflection of the discussion at the meeting.

**Approved documents**

The documents reviewed and approved at the meeting were:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [University of Edinburgh Insurance]		25 July 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [EL Certificate]		01 August 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [PL Confirmation]		21 July 2016
Evidence of Sponsor insurance or indemnity (non NHS Sponsors only) [CT Liability]		25 July 2016

GP/consultant information sheets or letters [About the Study]	1	26 June 2017
GP/consultant information sheets or letters [RMO letter]	1	26 June 2017
Participant information sheet (PIS) [PIS Forth Valley]	1	26 June 2017
Participant information sheet (PIS) [Patient Debrief Sheet-Forth Valley]	1	26 June 2017
Participant information sheet (PIS) [PIS State Hospital]	1	26 June 2017
Participant information sheet (PIS) [Patient Debrief-The State Hospital]	1	26 June 2017
Participant information sheet (PIS) [PIS Staff Forth Valley]	1	26 June 2017
Participant information sheet (PIS) [Staff Debrief- Forth Valley]	1	26 June 2017
Participant information sheet (PIS) [PIS Staff State Hospital]	1	26 June 2017
Participant information sheet (PIS) [Staff Debrief-The State Hospital]	1	26 June 2017
REC Application Form [REC_Form_05072017]		05 July 2017
Research protocol or project proposal [Study Protocol]	1	26 June 2017
Summary CV for Chief Investigator (CI) [CI CV]	1	26 June 2017
Summary CV for supervisor (student research) [Academic supervisor CV]		

### Membership of the Committee

The members of the Ethics Committee who were present at the meeting are listed on the attached sheet.

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

### After ethical review

#### Reporting requirements

The attached document “After ethical review – guidance for researchers” gives detailed guidance on reporting requirements for studies with a favourable opinion, including:

- Notifying substantial amendments
- Adding new sites and investigators
- Notification of serious breaches of the protocol
- Progress and safety reports
- Notifying the end of the study

The HRA website also provides guidance on these topics, which is updated in the light of changes in reporting requirements or procedures.

### User Feedback

The Health Research Authority is continually striving to provide a high quality service to all applicants and sponsors. You are invited to give your view of the service you have received and the application procedure. If you wish to make your views known please use the feedback form available on the HRA website: <http://www.hra.nhs.uk/about-the-hra/governance/quality-assurance/>

### HRA Training

We are pleased to welcome researchers and R&D staff at our training days – see details at <http://www.hra.nhs.uk/hra-training/>

With the Committee's best wishes for the success of this project.

Yours sincerely



For:

**Canon Matt McManus**  
**Vice Chair**

*Enclosures: List of names and professions of members who were present at the meeting*

*"After ethical review – guidance for researchers"*

Copy to: Charlotte Smith, University of Edinburgh  
Ms Allyson Bailey, NHS Forth Valley

## Appendix G- R&D Approval

Research and Development Approval Letters (Organised by health board then date, with most recent first)



Date: 8 Dec 2017  
Your Ref:  
Our Ref:  
Direct Line: 01324 214690  
Email: FV-UHB.RandD-depart@nhs.net  
R&D ref: FV1047

Ms Jane-Louise Jackson  
c/o Dr Clare Neil, Forensic Community Mental Health Service  
Westburn Building,  
Falkirk Community Hospital,  
Westburn Avenue  
Falkirk  
FK1 5SU

Dear Ms Jackson

**Study title: What promotes wellbeing of older-adults in secure forensic settings? Perceptions from older-adult forensic inpatients and staff.**

**REC reference: 17/WS/0161:**

**Amendment number: 1 (REC Ref AM02)**

**Amendment date: 16 November 2017**

Further to R&D management approval of this study on 11 August 2017, I am writing to confirm that NHS Forth Valley will accept the Amendment(s) detailed above as given a favourable opinion by the West of Scotland REC 5 on 7 December 2017.

Yours sincerely

A handwritten signature in black ink, appearing to read 'Andrew Murray', written over the printed name.

pp  
**MR. ANDREW MURRAY**  
Medical Director

CC: Claire Neil



Chairman: Alex Linkston CBE  
Interim Chief Executive: Fiona Ramsay

*Forth Valley NHS Board is the common name for Forth Valley Health Board  
Registered Office: Carseview House, Castle Business Park, Stirling, FK9 4SW*

[www.nhsforthvalley.com](http://www.nhsforthvalley.com) Facebook.com/nhsforthvalley @nhsforthvalley

List of documents approved:

<i>Document</i>	<i>Version</i>	<i>Date</i>
Letters of invitation to participant	2	13 November 2017
Notice of Substantial Amendment (non-CTIMP)	1	16 November 2017
Other [Letter detailing Amendment]		
Other [FV Patient Debrief Sheet]	2	17 November 2017
Other [GGC Patient Debrief Sheet]	2	17 November 2017
Other [TSH Patient Debrief Sheet]	2	17 November 2017
Other [RMO Letter]	2	17 November 2017
Other [FV Staff Debrief Sheet]	2	17 November 2017
Other [GGC Staff Debrief Sheet]	2	17 November 2017
Other [TSH Staff Debrief Sheet]	2	17 November 2017
Participant information sheet (PIS) [FV Patient Information sheet and Consent form]	4	13 November 2017
Participant information sheet (PIS) [GGC Patient Information sheet and Consent form]	2	13 November 2017
Participant information sheet (PIS) [TSH Patient Information sheet and Consent form]	4	13 November 2017
Participant information sheet (PIS) [FV Staff Information sheet and Consent form]	3	13 November 2017
Participant information sheet (PIS) [GGC Staff Information sheet and Consent form]	2	13 November 2017
Participant information sheet (PIS) [TSH Staff Information sheet and Consent form]	3	13 November 2017
Research protocol or project proposal	2	13 November 2017

Date: 17 Aug 2017  
Your Ref:  
Our Ref:  
Direct Line: 01324214690  
Email: FV-UHB.RandD-depart@nhs.net  
R&D ref: FV 1047

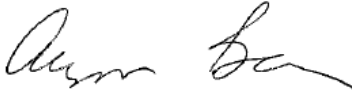
Ms Jane-Louise Jackson  
c/o Dr Clare Neil, Forensic Community Mental Health Service  
Westburn Building,  
Falkirk Community Hospital,  
Westburn Avenue  
Falkirk  
FK1 5SU

Dear Ms Jackson

**Study title: What promotes wellbeing of older-adults in secure forensic settings? Perceptions from older-adult forensic inpatients and staff.**  
**REC reference: 17/WS/0161:**

Further to the approval letter dated 11 August 2017, I note that you have received confirmation that PBPP approval is not required. I have confirmed Caldicott Guardian approval for NHS Forth Valley. You are therefore now able to continue with all aspects of your research. All other terms and conditions of the original approval remain in place.

Yours sincerely

  
pp  
MR. ANDREW MURRAY  
Medical Director

CC: Clare Neil

Date: 11 Aug 2017  
Your Ref:  
Our Ref:  
Direct Line: 01324214690  
Email: FV-UHB.RandD-depart@nhs.net  
R&D ref: FV 1047

Ms Jane-Louise Jackson  
c/o Dr Clare Neil, Forensic Community Mental Health Service  
Westburn Building,  
Falkirk Community Hospital,  
Westburn Avenue  
Falkirk  
FK1 5SU

Dear Ms Jackson

**Study title: What promotes wellbeing of older-adults in secure forensic settings? Perceptions from older-adult forensic inpatients and staff.**  
**REC reference: 17/WS/0161:**

Following the favourable opinion from the West of Scotland Research Ethics Committee on 5, I am pleased to confirm that I formally gave Management Approval to the study above on 11 August 2017. This approval is subject to the following conditions:

- You may not undertake any aspect of the study that is subject to the Public Benefit Privacy Panel until confirmation of their approval has been received.

This approval is granted subject to your compliance with the following:

1. Any amendments to the protocol or research team must have Ethics Committee and R&D approval (as well as approval from any other relevant regulatory organisation) before they can be implemented. Please ensure that the R&D Office and (where appropriate) NRS are informed of any amendments as soon as you become aware of them.
2. You and any local Principal Investigator are responsible for ensuring that all members of the research team have the appropriate experience and training, including GCP training if required.
3. If someone working within NHS Forth Valley is recruiting participants, those figures **MUST** be recorded on the EDGE research management system. If you have not used EDGE before, you should already have been offered training on the system. If recruitment is all being handled outside Forth Valley, you will be contacted monthly for the latest recruitment figures.
3. All those involved in the project will be required to work within accepted guidelines of health and safety and data protection principles, any other relevant statutory legislation, the Research Governance Framework for Health and Community Care and IHC-GCP guidelines. A copy of the Framework can be accessed via the Chief Scientist Office website at:  
<http://www.cso.scot.nhs.uk/Publications/ResGov/Framework/RGFEdTwo.pdf>



Chairman: Alex Linkston CBE  
Interim Chief Executive: Fiona Ramsay

Forth Valley NHS Board is the common name for Forth Valley Health Board  
Registered Office: Carseview House, Castle Business Park, Stirling, FK9 4SW

[www.nhsforthvalley.com](http://www.nhsforthvalley.com)  Facebook.com/nhsforthvalley  @nhsforthvalley

and ICH-GCP guidelines may be found at <http://www.ich.org/LOB/media/MEDIA482.pdf>


4. As custodian of the information collected during this project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT security policies, until the destruction of this data.

5. You or the local Principal Investigator will be required to provide the following reports and information during the course of your study:

- A progress report **annually**
- Report on SAEs and SUSARs if your study is a Clinical Trial of an Investigational Medicinal Product
- Any information required for the purpose of internal or external audit and monitoring
- Copies of any external monitoring reports
- Notification of the end of recruitment and the end of the study
- A copy of the final report, when available.
- Copies of or full citations for any publications or abstracts

The appropriate forms will be provided to you by the Research and Development office when they are needed. Other information may be required from time to time.

Yours sincerely



PP  
MR. ANDREW MURRAY  
Medical Director

CC: Clare Neil

	Chairman: Alex Linkston CBE Chief Executive: Jane Grant
	<i>Forth Valley NHS Board is the common name for Forth Valley Health Board Registered Office: Carseview House, Castle Business Park, Stirling, FK9 4SW</i>
	<a href="http://www.nhsforthvalley.com">www.nhsforthvalley.com</a>  <a href="https://www.facebook.com/nhsforthvalley">Facebook.com/nhsforthvalley</a>  <a href="https://twitter.com/nhsforthvalley">@nhsforthvalley</a>

Administrator: Sophie Bagnall  
Telephone Number: 0141 232 1826  
E-Mail: [sophie.bagnall@ggc.scot.nhs.uk](mailto:sophie.bagnall@ggc.scot.nhs.uk)  
Website: [www.nhsggc.org.uk/r&d](http://www.nhsggc.org.uk/r&d)

R&D Management Office  
West Glasgow ACH  
Dalnair Street  
Glasgow G3 8SW

8 November 2017

Ms Jane-Louise Jackson  
Trainee Clinical Psychologist  
NHS Forth Valley  
Falkirk Community Hospital  
Westburn Avenue  
Falkirk  
FK1 5QE

### NHS GG&C Board Approval

Dear Ms Jackson

Study Title:	What promotes wellbeing of older-adults in secure forensic settings? Perceptions from older-adult forensic inpatients and staff.
Principal Investigator:	Ms Jane-Louise Jackson
GG&C HB site	Leverndale Hospital and Rowanbank Clinic
Sponsor	University of Edinburgh
R&D reference:	GN17MH466
REC reference:	n/a
Protocol no:	Version 1 26/06/2017

I am pleased to confirm that Greater Glasgow & Clyde Health Board is now able to grant **Approval** for the above study.

#### Conditions of Approval

1. **For Clinical Trials** as defined by the Medicines for Human Use Clinical Trial Regulations, 2004
  - a. During the life span of the study GGHB requires the following information relating to this site
    - i. Notification of any potential serious breaches.
    - ii. Notification of any regulatory inspections.

It is your responsibility to ensure that all staff involved in the study at this site have the appropriate GCP training according to the GGHB GCP policy ([www.nhsggc.org.uk/content/default.asp?page=s1411](http://www.nhsggc.org.uk/content/default.asp?page=s1411)), evidence of such training to be filed in the site file

2. **For all studies** the following information is required during their lifespan.
  - a. Recruitment Numbers on a monthly basis

- b. Any change of staff named on the original SSI form
- c. Any amendments – Substantial or Non Substantial
- d. Notification of Trial/study end including final recruitment figures
- e. Final Report & Copies of Publications/Abstracts

**Please add this approval to your study file as this letter may be subject to audit and monitoring.**

Your personal information will be held on a secure national web-based NHS database.

I wish you every success with this research study

Yours sincerely,

A handwritten signature in black ink, appearing to read 'S. Bagnall', written in a cursive style.

Sophie Bagnall  
**Senior Research Administrator**

Jane-Louise Jackson  
Trainee Clinical Psychologist, NHS Forth Valley  
DClinPsychol Student, University of Edinburgh

Tuesday the 6<sup>th</sup> of June 2017

Dear Jane-Louise,

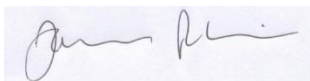
**Re: What promotes wellbeing of older-adults in secure forensic settings? Perceptions from older-adult forensic inpatients and staff.**

Many thanks for your revised research proposal in response to review by the TSH Research Committee in April 2017. The committee found the proposal to be an interesting piece of work, and I am happy to approve the study based on the revisions you have made. This letter will be copied to the Associate Medical Director along with evidence of your ethical approval or exemption, and the AMD will subsequently provide final management approval for the study to take place within TSH.

One condition of the research committees' approval is that you provide the committee with regular 6-monthly progress reports. This is an important mechanism by which the committee track progress, and is also a key component of our research governance processes.

If you require any further assistance, or have any feedback on the Research approval process then please do not hesitate to contact me.

Yours sincerely



**JAMIE PITCAIRN**  
**Research & Development Manager**  
**The State Hospital**

## Appendix H- Data Management Plan

### **Project Data Management Plan**

*Name of project:* What promotes well-being of older people in forensic inpatient settings? Perceptions from older inpatients and staff.

*Project Description:* A grounded theory methodological study of forensic mental health inpatients age 55+ years and staff in low, medium and high secure NHS facilities across Scotland.

*Funding Bodies:* NHS Forth Valley, NES, University of Edinburgh

*Principal Investigator:* Jane-Louise Jackson, Trainee Clinical Psychologist, NHS Forth Valley and Doctoral Student in Clinical Psychology, University of Edinburgh.

*Project Data Contact:* Jane-Louise Jackson ([s1580004@sms.ed.ac.uk](mailto:s1580004@sms.ed.ac.uk))

*Date of first version:* 2<sup>nd</sup> December 2016    *Date of last update:* 10<sup>th</sup> March 2017

*Related policies:* NHS Forth Valley data management policy, University of Edinburgh data management policy

### Data Collection

*Data description:* Digital recordings of semi-structured interviews and focus groups, digital word files of transcribed interviews, digital Dedoose files of analysed data, digital word files of demographic data and the researcher's logbook.

*Existing Data sets to be re-used:* None

*Methods of data collection:* Face to face semi-structured interviews and focus groups, recorded on an encrypted voice recorder. Notes taken in Principal Investigator's (PI) research logbook, to be typed up and stored digitally as a word file.

*Structures, Naming and Versioning systems:* e.g. 20170203\_DMP\_v2 (.5 used for minor changes, whole version number for more significant changes).

*Quality assurance processes:* Confirmation of unclear statements during interviews, potential to re-visit participants with themes drawn from data for their reflections on the data's accuracy.

#### Documentation and MetaData

*Documentation:* digital word files of transcribed interviews, Dedoose analysis files, Research log-book (electronic word file), Methodology in final written thesis (electronic document and published online University database), Methodology and justifications in research proposal (electronic document submitted to University of Edinburgh 29/10/16). Electronic files will be kept on NHS computer drives and the University of Edinburgh sharepoint for 10 years following Graduation from the University and post with NHS Forth Valley.

#### Ethics and Legal Compliance

*Ethics:* NHS multi-site R&D consent, Forensic Network multi-site, IRAS and University of Edinburgh ethics approval are all required for this project to go ahead.

NHS and the University of Edinburgh data management protocol for the storage and use of data must be adhered to.

To protect identity of participants, all transcriptions will be anonymised prior to uploading onto Dedoose. Personal details such as which setting patients or staff are from, age, medical status, name and other identifiable information will be removed from any quotes made from interview transcripts.

In order for data to be stored and transferred securely, interviews will be recorded on an encrypted voice recorder and voice files will be password protected and stored on the PI's NHS home drive. The voice recorder itself and all physical data (including research logbook, consent forms and demographic information) will be transported in a locked briefcase, which will be held by the PI at all times, or secured in the PI's car boot (during travel), locked home or office. Any remaining hard copies of notes or logs will be stored within the locked filing cabinet in the locked office at the Forensic Community Mental Health Service (FCMHS), Falkirk Community Hospital (NHS Forth Valley site).

*Copyright and Intellectual Property Rights:* Copyright and intellectual property rights for this project are held by the Principal Investigator, Ms Jane-Louise Jackson.

*Licence for re-use:* If approved for public sharing, data will be covered by the creative common licence.

*Restrictions on 3<sup>rd</sup> party use:* If approved for public sharing, data will be stored in the University of Edinburgh's data archive (PURE) and guidance as to its use will be stored as metadata. Those wishing to use the data will be required to sign an agreement to confirm that they will only use the data as per the guidance outlined in the metadata file.

#### Storage and Back Up

*Storage and Back up:* (From above- see ethics): In order for data to be stored and transferred securely, interviews will be recorded on an encrypted voice recorder and voice files will be password protected and stored on the PI's NHS home drive. Any remaining hard copies of notes or logs will be stored within the locked filing cabinet in the locked office at the FCMHS, Falkirk Community Hospital.

Data will be backed up on the PI's NHS home drive and password protected, as well as the University of Edinburgh's sharepoint cloud storage system and Dedoose (cloud storage).

The PI will be responsible for the saving, storage and back up of the data and reports. The NHS and University of Edinburgh will be responsible for providing two of these systems.

*Recovery procedures:* NHS Forth Valley's data recovery procedures will apply. In addition, the University of Edinburgh makes x2 back-ups of their sharepoint cloud storage system every day, as well as a disaster file protocol.

*Access arrangements:* Final data will be covered by access arrangements outlined by a terms of access confidential agreement. Whilst the research project is in progress, data will be shared via secure transfer/ joint access from the PI's academic and field/clinical supervisors via Dedoose, or a shared folder within the NHS Forth Valley home drive.

### Selection and Preservation

*Future research use:* In future Doctoral research projects whereby data of this nature is required to further develop theory and interventions. By the NHS in their service provision development and to evidence their current practise of the recovery model.

Data should be kept for 3 years and be held in Datashare v2.3, which comes at no cost to the PI.

The time required to prepare data for preservation is 2-3months as it requires collaboration with both the NHS and the University of Edinburgh. For data sharing, the PI has factored in 3months following viva for corrections and submission to selected journals.

### Data Sharing

Data will be stored on the University of Edinburgh's Datashare v2.3.

A data sharing agreement will be drawn up with the PI, NHS and University of Edinburgh to ensure each stakeholder's data protection policy is adhered to.

Data will be published as soon as possible following viva.

The PI's academic supervisor will be consulted to obtain a persistent identifier for the data.

### Responsibilities and Resources

*Named person responsible for implementation of the Data Management Plan:* Jane-Louise Jackson, Principal Investigator

*Named person responsible for each data management activity:* Jane-Louise Jackson, Principal Investigator

*Hardware or Software required:* Dedoose (cost covered by the University of Edinburgh)

*Additional specialist expertise or training required:* Continuing development of interview skills (PI), continuing development of qualitative data analysis skills (PI), relevant security training, e.g. breakaway (PI)

*Charges to be applied by data repositories:* UK Data Archive (covered by the University of Edinburgh)

# Appendix I- Information Sheets

Empirical Study: Participant Information Sheets and Consent Forms (patient then staff) used for recruitment in NHS Forth Valley.



*What promotes wellbeing of older-adult forensic mental health inpatients?*



## **Participant Information Sheet and Consent Form**

*What promotes wellbeing of older-adult forensic mental health inpatients?*

You are being invited to take part in a research study. Please take time to read the following information carefully and take time to decide whether or not you wish to take part.

### **What is this study about?**

This study aims to find out what matters to people as they get older. This will be done by talking to patients over the age of 55 years and staff in NHS wards.

### **Why have I been invited?**

You have been asked to take part as you are aged 55 years or over. This study would like to find out what is important to you.

### **Do I have to take part?**

No, it is up to you. If you decide to take part you are still free to withdraw any time, without giving a reason. Your decision will not affect the healthcare that you receive, or your legal rights.

### **What will happen if I take part?**

Jane-Louise Jackson, Trainee Clinical Psychologist, will arrange to visit you at the ward so you can ask questions about the study before signing a consent form. She will then spend up to one hour talking to you about what matters to you. There are no right or wrong answers, this study is interested in your opinions.

Your Responsible Medical Officer (RMO) will be informed that you have taken part in this study.

After this, Ms Jackson will contact health records to ask for some demographic information (your age, gender, diagnosis and date of admission). She will then meet other patients and staff. You might be asked to meet her again (within 1 year) to say what you think about the types of things others have spoken about.

### **Will what I say be kept private?**

Yes. Information collected during this study will be kept confidential. The meetings will be audio recorded, so please do not tell Ms Jackson specific information about incidents or names of people, dates and locations. This is to keep confidentiality and make it more comfortable for you and other people to give your opinions. The audio file will be deleted from the recorder when it is typed up and the anonymous data will be kept in a locked filing cabinet or on secure computer systems (NHS, University of Edinburgh, Dedoose analysis software). Only Ms Jackson and her supervisors will have access to these. If you give information about yourself or others being harmed in the past or at risk of harm in the future, Ms Jackson will have to pass this on to your clinical team.

### **What are the possible disadvantages of taking part?**

It may be difficult to talk about your opinions, especially if you have had a negative experience on the ward or worry about the future. It is up to you what you talk about. Afterwards, your clinical team can help if you found taking part in this study difficult. Please talk to your keyworker on the ward for support if you can.

### **What are the possible benefits of taking part?**

Your views are very important in helping the NHS care for people. You may also feel benefit from having had time to talk about your experiences and give your opinions.



**What will happen to the findings of this study?**

You will be invited to a presentation of the findings and/or offered a written summary. The results will be written up as a report and submitted as a thesis to the University of Edinburgh. A report may also be written for publication and/or circulation within the NHS. No information that could identify you or anyone else will be included in these.

**Any worries?**

If you have any other questions, you can telephone and leave a message for Ms Jackson on 01324 616 211 (c/o Dr Clare Neil, NHS Forth Valley).

If you would like to discuss this study with someone independent of the study please contact Charlotte Clarke, Head of School of Health in Social Science, University of Edinburgh on 0131 650 4327.

If you wish to make a complaint about this study, please contact NHS Forth Valley:

Patient Relations,  
Forth Valley Royal Hospital  
Stirling Road, Larbert  
FK5 4WR  
Phone: 01324 566660  
Email: [fv-uhb.complaints@nhs.net](mailto:fv-uhb.complaints@nhs.net)



### CONSENT FORM

*What promotes the wellbeing of older-adult forensic mental health inpatients?*

*Ms Jane-Louise Jackson, c/o Dr Clare Neil, FCMHS, NHS Forth Valley*

**Please initial box**

- 1. I confirm that I have read and understand the information sheet (13/11/17, v4) for the above study and have had the opportunity to ask questions.
- 2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
- 3. I understand that the interviews will be audio recorded.
- 4. I understand that data collected during the study will not have any information in it that can identify me or others, and can be accessed by Ms Jackson and her supervisors in the NHS and University of Edinburgh. I give permission for these individuals to have access to this data.
- 5. I understand that my RMO will be informed that I have participated in this study.
- 6. I agree that Ms Jackson can request my demographic information (as noted above) from health records.
- 7. I agree to my anonymised data being used in future ethically approved studies.
- 8. I agree to being contacted (at the ward, within 12months of my participation) to be invited for a follow-up interview, or to a presentation of the study's results.
- 9. I agree to take part in this study.

Name of Participant	Date	Signature

Name of Person taking consent	Date	Signature



## **Participant Information Sheet and Consent Form**

*What promotes wellbeing of older-adult forensic mental health inpatients?*

You are being invited to take part in a research study. Please take time to read this information carefully and take time to decide whether or not you wish to take part.

### **What is the purpose of the study?**

This study aims to explore the wellbeing of forensic mental health inpatients as they get older. This will be done by talking to patients over the age of 55 years and staff in NHS wards.

### **Why have I been invited?**

You have been invited as a member of clinical staff. This research wants to find out what you think is important to older-adult forensic mental health inpatients in the ward in which you work.

### **Do I have to take part?**

No, it is up to you whether or not you take part. If you decide to take part you are still free to withdraw at any time, without giving a reason. Your decision will not affect your employment.

### **What will happen if I take part?**

You will be asked to attend a one-hour focus group (with other clinical staff) or have a 1:1 discussion in your place of work, with Ms Jane-Louise Jackson, Trainee Clinical Psychologist. You can ask questions before giving your consent to take part. You will be asked for your opinions on ageing in the ward where you work. If you choose to, you might be asked to meet again with Ms Jackson within one year, to give your views what other individuals and groups have said.

### **Will the information I give to this study be kept confidential?**

Yes. Information collected during this study will be kept confidential. The focus groups and discussions will be audio recorded, so please do not tell Ms Jackson specific information about incidents or names of people, dates and locations. This is to keep confidentiality and make it more comfortable for yourself and others to give their opinions. The audio file will be deleted from the recorder when it is typed up and data will be kept in a locked filing cabinet or on secure computer systems (NHS, University of Edinburgh, Dedoose analysis software). Only Ms Jackson and her supervisors will have access to them. Should you disclose any information which suggests professional malpractice and/or a risk of harm to yourself or others, Ms Jackson will have to share this information with the relevant parties.

### **What are the possible disadvantages of taking part?**

It may be difficult to give opinions, especially if you have had a negative experience working on the ward or worry about ageing. It is up to you what you talk about. You can contact occupational health in your NHS board, should you feel any ill-effects from your participation (including free of charge employee counselling). Please see your local NHS board intranet for details of this.

### **What are the possible benefits of taking part?**

Your views are very important in informing patient care and you may see some benefit in your working relationships (with colleagues and patients).



*What promotes wellbeing of older-adult forensic mental health inpatients?*



**What will happen to the findings of this study?**

You will be invited to a presentation of the findings and/or offered a written summary. The results will be written up as a report and submitted as a thesis to the University of Edinburgh. A report may also be written for publication and/or circulation within the NHS. No information that could identify you or anyone else will be included in these.

**Any concerns?**

You can contact your manager if you have any concerns about having taken part in this study.

If you have any further questions, you can telephone and leave a message for Ms Jackson on 01324 616 211 (c/o Dr Clare Neil, NHS Forth Valley).

If you would like to discuss this study with someone independent of the study please contact Charlotte Clarke, Head of School of Health in Social Science, University of Edinburgh on 0131 650 4327.

If you wish to make a complaint about this study, please contact NHS Forth Valley:

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What promotes wellbeing of older-adult forensic mental health inpatients?



## CONSENT FORM

What promotes the wellbeing of older-adult forensic mental health inpatients?

Ms Jane-Louise Jackson, c/o Dr Clare Neil, FCMHS, NHS Forth Valley

Please initial box

1. I confirm that I have read and understand the information sheet (13/11/17, v3) for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason.
3. I understand that the interview(s)/focus group(s) will be audio recorded.
4. I understand that data collected during the study will not have any information in it that can identify me or others, and can be accessed by Ms Jackson and her supervisors in the NHS and University of Edinburgh. I give permission for these individuals to have access to this data.
5. I agree to my anonymised data being used in future ethically approved studies
6. I agree to being contacted (via my manager, at the ward, within 1 year of my participation) to be invited for a follow-up interview, or to a presentation of the study's results.
7. I agree to take part in this study.

\_\_\_\_\_  
Name of Participant                      Date                      Signature

\_\_\_\_\_  
Name of Person taking consent                      Date                      Signature

## Appendix J- Debriefing Sheets

Empirical Study: Participant Debrief Sheets (patient then staff) used for recruitment in NHS Forth Valley



*What promotes wellbeing of older-adult forensic mental health inpatients?*



### Participant Debrief Sheet

*What promotes wellbeing of older-adult forensic mental health inpatients?*

Thank you for taking part in this study.

What we have discussed will now be typed-up (taking out any information that could be used to identify you or others) and used to guide future interviews and the results of the study.

The audio recordings of all interviews will be deleted once the study is complete. Anonymous written record(s) of our discussion(s) will be kept for up to 10 years electronically on secure computer systems in the NHS and University of Edinburgh. The information you gave on your age, gender etc. as well as your consent form will be kept separately in a locked filing cabinet within the Forensic Clinical Psychology Department, Forensic Community Mental Health Service, NHS Forth Valley and destroyed on completion of the study.

A report will be written about the study and its results. You will be invited to a presentation of the results at an NHS site and/or you will be offered a short, written summary. You will not be identified in any published results.

#### **Any worries?**

Afterwards, your clinical team can help if you found taking part in this study difficult. Please talk to your keyworker on the ward for support if you can.

If you have any other questions, you can telephone and leave a message for Ms Jackson on 01324 616 211 (c/o Dr Clare Neil, NHS Forth Valley).

If you would like to discuss this study with someone independent of the study please contact Charlotte Clarke, Head of School of Health in Social Science, University of Edinburgh on 0131 650 4327.

If you wish to make a complaint about this study, please contact NHS Forth Valley:

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Email: [fv-uhb.complaints@nhs.net](mailto:fv-uhb.complaints@nhs.net)

Thank you again for participating.

Jane-Louise Jackson, Trainee Clinical Psychologist  
NHS Forth Valley Psychology Services / University of Edinburgh



*What promotes wellbeing of older-adult forensic mental health inpatients?*



## **Participant Debrief Sheet**

*What promotes wellbeing of older-adult forensic mental health inpatients?*

Thank you for taking part in this study.

The views expressed in your focus group will now be looked at and used to inform questions asked in future groups and individual interviews. All information that could identify you, or anyone else will be removed when typing-up the audio recordings and the audio files will be deleted at the end of the study.

The study and its results will be written up as a report. You will either be invited to a presentation of the results in the NHS or you will be offered a short written summary.

### **Data Storage**

Anonymised transcriptions of focus groups will be kept for up to 10 years in electronic form, on the NHS Forth Valley IT systems and University of Edinburgh DataVault. Demographic information and consent forms will be kept in a locked filing cabinet within the Forensic Clinical Psychology Department, Forensic Community Mental Health Service, NHS Forth Valley and destroyed on completion of the study.

### **Any concerns?**

You can contact your manager if you have any concerns about having taken part in this study.

You can contact occupational health in your NHS board, should you feel any ill-effects from your participation (including free of charge employee counselling). Please see your local NHS board intranet for details of this.

If you have any further questions, you can telephone and leave a message for Ms Jackson on 01324 616 211 (c/o Dr Clare Neil, NHS Forth Valley).

If you would like to discuss this study with someone independent of the study please contact Charlotte Clarke, Head of School of Health in Social Science, University of Edinburgh on 0131 650 4327.

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Thank you again for participating.

Jane-Louise Jackson, Trainee Clinical Psychologist  
NHS Forth Valley Psychology Services / University of Edinburgh

## Appendix K- Coding Sample

### Empirical Study: Coding Example

Raw data	Initial codes	Focussed codes
<p>You can't have too much patience can you? You know because if you didn't...if my patience ran out there'd be tables and everything flying up in the air...that's the way that I, because that's the way I see it done and I don't go down that road anymore</p> <p><i>Have you more patience now than before?</i></p> <p>Aye, yes</p> <p><i>What do you think that's to do with?</i></p> <p>Aye, that's what I do, I write slow and gentle on my hand, 'S&amp;G' so I remember to go slow and gentle instead of going about banging doors I shut them gentle. Aye I love being slow and gentle, even when I write now I don't press hard when I'm painting nice and gentle when I dip it in and it makes me feel dead mellow (sigh), like a better person, instead of all that rushing, rushing, rushing.</p> <p><i>What's helped you?</i></p> <p>Well to be honest with you, eh, the stay here has really helped me. It's helped me amazingly, I can't thank them..eh..thank them enough.</p>	<p>Having patience</p> <p>Losing temper in past</p> <p>Seeing others behaviour</p> <p>Managing reactions differently now</p> <p>Having more patience</p> <p>Writing coping phrases</p> <p>Going slowly and gently</p> <p>Feeling mellow</p> <p>Being a better person</p> <p>Having rushed before</p> <p>Being helped by hospital</p> <p>Hospital being amazing</p> <p>Thanking hospital</p>	<p>Having changed</p> <p>Helping self</p> <p>Taking more time</p> <p>Having changed</p> <p>Feeling grateful</p>

## Appendix L- Sample Memos

Empirical Study: Memo Examples

### ***Freewriting- a post interview memo***

There was lots of repetition in today's account and the patient avoided answering questions, instead telling me about the injustice of his situation. It seems likely that he was keen to get his sense of injustice across, but possibly not due to lack of insight into his offence. It may be that the person's long admission feels unjust to them, as well as the uncertainty regarding their future. There would have been the potential that he would have been discharged from prison sooner, if he had gone there rather than hospital. He also seemed to resent some others for what he saw as a more fair experience.

This patient appeared very keen to be liked and put across his achievements and skills. This reflected other patient participants' accounts and may relate to needing to be recognised for more than their offence or mental ill-health ?being seen as good or being good? Pre-occupation at times with patients outside clinic room.

Prior to recording this patient showed me written references from staff which detailed the good in this character. Showed me photographs of family- I wonder if this is to do with being seen by me as a human rather than a mental health patient ?normalising ?being relatable. He seemed to want to explain his past and came prepared with a written account of his admission so far and asked me to read it before turning on the audio recorder. Sense of injustice and missing out/wasting life. I agreed as I felt it was transactional, with him then giving me the time in the interview. However this then did not leave him as much time as he wanted to speak in the interview, which is likely to have limited the opportunity for us to fully explore some areas. Taking this forward into the next interview, I want to think more about session management, in terms of planning additional time per patient and capturing data in the audio recordings by referring to and encouraging reflection on information given post consent but pre-recording.

**Clustering- example analytic memos**

