Ref 11/1024/06

Full title of project:

Characteristics and needs of long-stay patients in high and medium secure forensic-psychiatric care: Implications for service organisation

Aims and objectives:

Aims:

Forensic-psychiatric high and medium secure services are costly to the NHS and very restrictive for patients. Clinical experience and the limited research available in this area indicate that they are not always used in the most cost-efficient way, e.g. that some patients stay for too long periods of time in highly restrictive and expensive secure settings. A proportion of patients may require long-term, potentially life-long, secure forensic-psychiatric care but their mental health, psychosocial and service needs are not met by existing service provision designed for faster throughput. The overall aim of this project is to improve the quality and cost-efficiency of care and management of patients who stay for prolonged periods in high and medium secure forensic-psychiatric settings. This will be achieved through a survey of long-stay patients (defined here as patients staying for more than 5 years in medium secure or more than 10 years in high secure care) , an analysis of their characteristics, needs and treatment pathways using detailed case analyses and clinician interviews, qualitative interviews with patients and extensive consultation of stakeholders (responsible clinicians, managers, commissioners, policy makers and service users) to inform the development of services that are cost-efficient, meet the needs, legal and ethical challenges of this unique patient group and are acceptable to service users. Particular attention will be paid to the translation of findings into clinical service innovation and its potential hindrances. Potential service models will be developed with a view of future evaluation.

Objectives:

(1) Length of stay in secure care

We will identify

- the length of stay (LoS) profiles of the current high and medium secure population in England
- the estimated number of long-stay patients in these settings

(2) Characteristics and needs of long-stay patients

We will describe

- characteristics of long-stay patients including sociodemographics, psychopathology, criminal history and risk
- their care pathways and reasons for prolonged stay
- their current and future mental health, psychosocial and service needs through file review and interviews with responsible clinicians;
- and develop a categorisation of long-stay patients according to current presentation and future need

(3) Patient experience of long-stay

Using qualitative patient interviews we will identify

- patients' perceptions of their treatment pathways, long-terms needs and acceptable service provision to maximise their quality of life
- effects of prolonged stay in secure settings on quality of life

(4) Service innovation

Using expert interviews, stakeholder consultation, workshops and a Delphi exercise we will

- describe existing service models for long-stay secure forensic-psychiatric care in the Netherlands and Germany
- describe essential and desirable characteristics of long-stay forensic units
- explore the ethical and legal challenges of such care drawing on the experience from other countries
- explore the views of clinicians, managers , commissioners and policy makers on long-stay forensic care and identify potential hindrances regarding their implementation

- develop potential service models and make recommendations regarding their implementation and evaluation, including economic evaluation

Research questions:

- What is the length of stay (LoS) profile of the current high (HSS) and medium secure (MSU) forensic-psychiatric population in England? (Work package - WP - 1)
- How many long-stay patients are currently resident in high or medium secure care? (WP 1)
- What are the characteristics, care pathways and mental health, psychosocial and service needs of these long-stay patients? (WP 2)
- Which patient and non-patient factors are associated with long-stay? (WP 2)
- Are there different categories of long-stay patients with distinct needs and, if so, what are they? (WP 2)
- What are the experiences of long-stay patients in forensic care? (WP 3)
- What are the ethical and legal issues associated with long-stay secure forensic services? (WP 4)
- Which service models could meet the needs of the different long-stay groups, improve resource use and quality of life of this patient group and what are factors potentially impeding their implementation? (WP 4)

Our data will be crucial in informing much needed service development for long-stay forensic-psychiatric patients and will form the basis for future evaluation, including economic, of such services.

Background:

Forensic-psychiatric services provide care and treatment for mentally disordered offenders (MDOs) in high, medium, and low secure in-patient facilities as well as in the community. This project concentrates on high and medium secure services as (a) their remit is most clearly defined, (b) they are high cost/low volume services, and (c) they pose significant restrictions upon patients and hence raise considerable ethical challenges. There are currently three high secure hospitals in England, Broadmoor, Ashworth and Rampton, catering in total for around 750 patients [1]. Medium secure services were developed in the late 1970ies and early 1980ies to bridge the gap between high secure and general psychiatric care. At present there are around 3500 medium secure beds in about 60 units, nearly two fifths provided in the independent sector.

Forensic-psychiatric high and medium secure services are costly to the NHS. Bed costs for high secure provision are approximately £275 000 per annum per patient, in medium secure care this figure is about £175 000, consuming £1.2 billion per annum, 1% of the entire NHS and 10% of the mental health budget [1,2]. It follows that such services need to be targeted at those who actually require and benefit from them, and that individuals ought not to be detained in these settings if they no longer need this type of care. Nevertheless, clinical experience and research findings (cited below) suggest that secure forensic services are not always used in a cost-efficient way with patients staying for too long in too restrictive settings, no longer needing or benefitting from the interventions offered. Through blocking of resources, inappropriately long stay not only impedes rehabilitation of individual patients but also impairs capacity of services to address the needs of patients with more acute presentations.

Concerns that a number of patients stay for too long in too high levels of security have been raised in studies in the 1990's and early 2000nds highlighting that between one third and two thirds of patients resident in high secure settings do not require that level of security [3-8]. Inadequate provision of medium secure beds was thought to be a significant factor in the delayed transfer of patients to more appropriate levels of security. These findings led to a central drive by the Department of Health to increase medium secure capacity while bed numbers in the high secure estate have reduced [9,10].

Length of stay:

There is no accepted standard for length of stay (LoS) in either high or medium secure care. For high secure care, the median LoS of those currently resident is 4.1 years while the mean LoS based on discharge cohorts is around 8 years. Preliminary work for this application has identified, however, that a significant proportion of patients continue to remain in high secure care for extended periods of time, eg. 16% for over 10 years (see Fig.

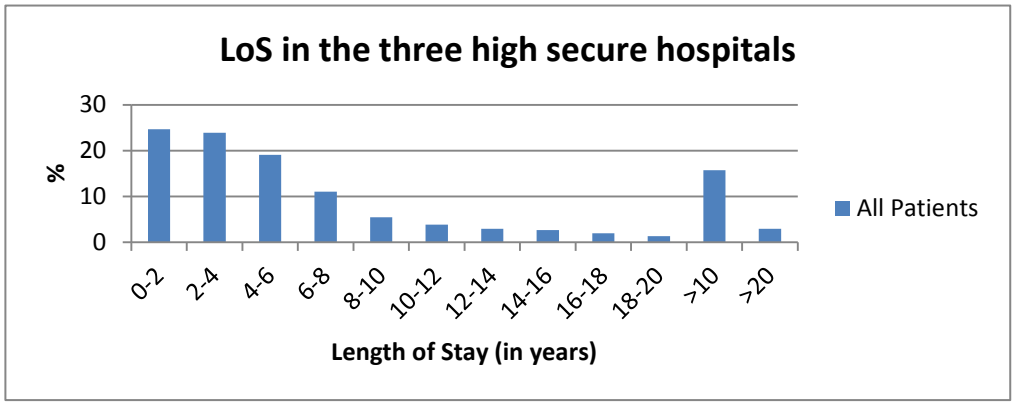
1). For medium secure care, the original guidance from government, based on the recommendations in the Glancy [11] and Butler [12] report, suggested an upper limit of LoS of 2 years. While early studies, using medium secure unit (MSU) discharge samples, identified LoS roughly in this region [13-15], later research and studies using cross-sectional samples of in-patient populations have identified an increasing trend for patients to be detained far in excess of this, with between 10 and 20% staying 5 years or longer [1,7,16-19]. In addition, as almost all high secure patients 'step-down' to medium secure care before being discharged back to the community, LoS in the two tiers of security may add up leading to very lengthy and costly overall periods of incarceration in highly restrictive environments.

For the purpose of this application we will use a LoS of over 10 years in high secure and over 5 years in medium secure care as a cut-off to define 'long-stay' as our working definition based on previous literature, practical considerations and experience of service provision both within and outside the UK. For HSS, only Dell et al [20] have used the term 'long-stay' which they defined as LoS of over 8 years. However, their study used a discharge cohort while we will investigate current patient populations. In addition, a cut-off of 8 years would include nearly one third of the current HSS population which appears a too high percentage to capture what we believe should be the more extreme end of LoS. Our proposed cut-off of 10 years is just above the mean LoS + one standard deviation, capturing around 15% of the population. This is roughly in line with 'long-stay' populations in those countries which have developed specific long-stay units, which typically cater for about 10 – 20% of the total forensic population. For medium secure care a cut-off of 5 years is similarly likely to capture 15 – 20% of the total current population.

Despite ongoing concerns that some patients remain in high secure care for far longer than average and the increasing LoS in medium secure settings, research attempting to identify determinants of long stay is limited. One early study at Broadmoor Hospital [20] identified severity of index offence as most important factor for personality disordered patients, while for those with mental illness psychopathology was a more relevant predictor of LoS. Studies in medium secure settings have identified severity of psychopathology, psychiatric history, seriousness of offending, patients being on 'restriction orders' (requiring Ministry of Justice permission for transfer), non-engagement in interventions, dependency needs and lack of step-down facilities as factors associated with long-stay [13,14,18,19,21,22].

A proportion of patients who have been detained in high or medium forensic settings for prolonged periods could move to other settings if appropriate provision was available. However, there is a significant proportion, at least one quarter of patients resident in high or medium secure settings, who may require long-term secure forensic care, some life-long [4,7,8,23]. What the mental health, psychosocial and service needs of this population are and how to best meet them remains unclear. McKenna et al. [14] noted that patients in high secure care thought to require long-term medium secure provision are less disturbed than those in general psychiatric high dependency settings. Coid & Kathan [24] cautioned against modelling long-term medium secure care too closely on traditional MSU provision as those requiring these services may have more similarities with high secure than medium secure patients. Therefore, it is likely that the population requiring secure forensic care on a long-term basis is not a homogenous group [25], and that their needs cannot be met by one service model. However, it is apparent that current services, designed to accelerate throughput and providing intensive treatment with a view to rehabilitation back into the community, are not appropriate for this group of patients. They would appear to require a new type of service, focusing on quality of life rather than resource-intensive therapeutic interventions, which they mostly had been offered or completed with limited success. Such service does not currently exist in England.

Fig 1 LoS in high secure care based on current population (Aug 2011)



Limitations of previous research:

It is apparent from the above that research to date has notable limitations: (a) it is largely based on MSU samples from single units, (b) it has paid little attention to the specific *needs* of long-stay patients, (c) it has not attempted to describe distinct groups of long-stay patients according to clinical and risk characteristics and long term service needs, (d) it has almost exclusively relied on quantitative research methods, (e) it has not explored the views of long-stay patients on their experience of care and desired service provision, (f) it has not explored the significant ethical and legal challenges of long-term, possibly life-long, secure forensic care, (g) it has not taken into account international evidence and experience regarding best practice for the provision of long-term secure forensic care and (h) it has not attempted to translate findings into outputs relevant to the development of services for the long-stay group of patients.

Services for long-stay forensic-psychiatric patients:

Given the above, it is not surprising that only very few forensic units in England have begun to develop services for patients with long-term needs, labelled as 'rehabilitation' or 'slow stream' services or services for those with 'treatment-resistant' disorders rather than recognising openly the long, potentially life-long, nature of the service. The development of services for this patient group has been at best patchy, uncoordinated and not based on a thorough assessment of the population served, their needs and possible service models to meet these needs. Notably, there is currently no local or national strategy for the management of this patient group.

A review of the international literature as well as of information gathered by the Special Interest Group (SIG) on long-term forensic care of the International Association of Forensic Mental Health Services (IAFMHS) and the Dutch Expertise Centrum for Forensic Psychiatry (EFP) indicated that there are currently two European countries that have responded proactively to the needs of these patients, the Netherlands and Germany where long-stay units have been developed, demonstrating cost savings (long-stay wards in the Netherlands attract half the costs compared to treatment wards) as well as increased patient satisfaction due to their focus on quality of life. While provision in Germany varies locally, the Netherlands have a national strategy for long-stay forensic care and have provided specific long-stay forensic units since 1999. There are currently 200 long-stay beds in different units (equating to about 10 – 15 % of the forensic population). Patients admitted to long-stay care are those thought to have no realistic prospect of discharge after treatment of at least 6 years duration in two different treatment units.

The implementation of international service models in the UK context maybe be challenging due to differences in funding, service provision, governance and legal frameworks. A systematic exploration of such differences to establish the potential for transfer of such models alongside a detailed description of the characteristics and needs of long-stay patients in UK forensic services will enable the development of evidence-based policy and tailored services meeting the needs of different groups of long-stay patients. Therefore the findings of this project will be of considerable value to policy makers, commissioners, managers and clinicians in the development of such services. Patients will benefit from services that meet their specific needs in the least restrictive environment.

Need:

Research into mental ill health has been identified as an area of weakness in UK research and targeted investment to build research capacity has been called for. Forensic mental health has been highlighted as an area of underfunding within mental health research [26]. No SDO projects have been funded so far investigating specifically forensic populations detained in secure psychiatric care. However, patients have expressed their preference for receiving care in the least restrictive environment, and research into the research priorities of forensic patients reveals that they consider it important to find out more about how length of stay can be reduced [27].

This project aims to provide crucial data for service organisation on a group of patients with chronic and complex needs who are detained in high and medium secure forensic-psychiatric settings for extended periods of time. Ongoing financial constraints on NHS budgets and the large cost of high (approx. £275,000 per annum per patient) and medium (approx. £175,000 per annum per patient, totalling £1.2 billion or 1% of the entire or 10% of the mental health NHS budget) [2] secure services highlight the importance of utilising these resources effectively and efficiently. In addition, secure forensic-psychiatric services pose significant restrictions upon patients putting an ethical obligation on clinicians and service providers to (a) identify and move on those patients who no longer need care in such settings, and (b) provide care in the least restrictive environment, enhancing quality of life and targeted at their specific needs, for those patients who require secure care on a long-term basis. In spite of this, concerns have been raised that a significant proportion of patients stay in too high levels of security for too long, that LoS in secure forensic settings is rising and that the mental health, psychosocial and service needs of long-stay patients are not met by current service provision [1,3-8,16,17,19].

Although some research has been conducted identifying factors associated with long stay [13,14,19,21,22], a detailed analysis of the current long-stay cohort, including patient and non-patient parameters determining long-stay, treatment pathways and long-term needs, is lacking. Pilot expert interviews in preparation of this application suggest that the long-stay group may consist of patients with very different characteristics and needs, e.g. those who, despite high levels of specialised interventions, suffer chronic, severe pathology with ongoing high risk to others, those who consistently decline engagement and therefore, through non-completion of relevant intervention programmes, remain at high risk, those who are of lower risk to others but cannot move on due to a lack of service provision catering for their specific needs, 'high profile' cases, ie. patients who, despite having made progress in treatment, are not rehabilitated back into the community due to political reasons (eg. 'the Yorkshire Ripper'), and those who do not wish to live independently and may be institutionalised. However, no empirical research is available to support such categorisation. Furthermore, very little is known about the experience of patients who have been detained in secure settings for extended periods of time.

This project aims to generate knowledge to fill these gaps in order to provide policy makers, commissioners, managers and clinicians with crucial information for the planning of services that are cost-effective and efficient, safe, targeted at the specific needs and enhance the quality of life of long-stay forensic-psychiatric patients. Crucially, it aims to use this knowledge to stimulate service innovation through ongoing involvement of policy makers, commissioners and managers, recommendations for the development of long-stay services and exploration of ethical and legal issues and other barriers to the implementation of such service models.

This research proposal has been prompted by the expressed need for data on long-stay forensic patients within the NHS management community in order to inform service development and by patients' experiences of secure forensic-psychiatric care. The specific research questions to be addressed were developed in two meetings, followed up by phone conversations, involving senior clinicians, the Associate Medical Directors of all three high secure hospitals, managers from medium secure units, commissioners and representatives from the Ministry of Health. A Project Advisory Group comprised of policy makers, commissioners, managers, senior clinicians and researchers has been developed to meet regularly throughout the lifetime of this project to ensure it is guided by the needs of the NHS and to maximise impact on service innovation. Links between the researchers and the Steering Group will facilitate the smooth implementation of findings from this research.

The Project Advisory Group will be complemented by two international advisors from the Netherlands and Germany, countries that have developed specific services for long-stay forensic patients demonstrating significant cost savings while increasing patient satisfaction. Some applicants of this proposal and of the Project

Advisory Group are part of an international network on long-term forensic-psychiatric care, the Special Interest Group of the International Association of Mental Health Services, which will ensure the research remains informed by the most up to date knowledge and best practice internationally.

A draft proposal was presented to service users with experience in secure forensic care and amendments were made following their input. A Service User Group has been established which will meet throughout the life time of the project and feed into the Project Advisory Group. This will facilitate patient recruitment and engagement with the research and will be crucial to ensure any service innovations informed by this research are relevant and acceptable to the users of these services.

Methods:

This proposed study consists of four work packages (WPs) to achieve the aims and objectives and address the research questions described above. All WPs have been developed in close collaboration with service users.

- WP 1 will use a cross-sectional design to identify the LoS profile of the current high and medium secure population in England and estimate the total number of long-stay patients
- WP2 will describe the clinical and risk characteristics of the long-stay population and identify their care pathways and needs using detailed file reviews and clinician interviews. It will establish factors associated with prolonged stay and develop a categorisation of different groups of long-stay patients.
- WP3 will use qualitative interviews to describe patients' perspectives on long-stay including experience of treatment pathways, strengths and weaknesses of current service provision with a view of extrapolating key characteristics of acceptable long-term services
- WP 4 will identify which service models could meet the needs of different groups of long-stay patients and improve efficiency of service delivery and quality of life of service users, and what factors, including ethical and legal ones, might impede their implementation

Work package 1: Length of stay in secure care (months 1 – 6)

This cross-sectional study will collect data on LoS (from admission to current setting to census date) and basic patient characteristics (date of birth, gender, ethnicity, admission source, Mental Health Act section) of all patients resident on one census date at the three high secure hospitals and a representative sample of approx. 45% of medium secure units. Due to the particular ethical challenges and resource implications of providing care in conditions of high security, all patients in all three high secure hospitals will be included (see Table 1 – figures are based on preliminary data collection in preparation for this application). These hospitals have, as part of the preparatory work for this application, already identified the appropriate clinical and information governance contacts to assist with the collection of the required data, have advised on routinely collected – and hence readily available – data and have supplied data for preliminary analysis.

Sample:
Comprehensive information on medium secure forensic services is difficult to obtain and has to be drawn from a variety of sources. In preparation for this project we have identified current NHS and independent sector MSUs through the Royal College of Psychiatrists, the Quality Network for Medium Secure services, a research active network of medium secure providers aiming to standardise service provision across England, regional commissioners and personal contacts with other researchers and senior clinicians. Information on size and specification of units was followed up by telephone if required, providing us with a relatively complete picture of current medium secure care.

Table 1 High secure units and patient numbers for WP 1 to 3

Name of unit	Gender of patients	Patients, total (WP 1)	Expected number of long-stay patients (WP 2)	Randomly selected patients to be interviewed (WP 3)
Ashworth	Male	207	39	10 in total
Broadmor	Male	199	35	

Rampton	Both	345	44	
		749	**118**	

Table 2 Medium secure units and patient numbers for WP 1 to 3

Region	Total number of units in region	Units included	NHS/ Independent	Gender of patients	Patients, total (WP 1)	Expected number of long-stay patients (WP 2)	Randomly selected patients to be inter-viewed (WP 3)
North East	3	Ridgeway	NHS	Both	74	15	20 in total, stratified according to category of long-stay
North West	10	Edenfield Centre	NHS	Both	100	20	
		Scott Clinic	NHS	Both	56	11	
		Calderstones	NHS	Both	53	11	
		The Spinney	independent	Male	80	16	
		The Priory Widnes	independent	Male	24	5	
Yorkshire	4	Humber Centre	NHS	Both	95	19	
		Stockton Hall	independent	Both	144	29	
East Midlands	5	Arnold Lodge	NHS	Both	92	18	
		St Andrew's NNH	independent	Both	183	37	
West Midlands	5	Raeside Clinic	NHS	Male	90	18	
		St Andrew's Birmingham	independent	Male	30	6	
East of England	9	Norvic Clinic	NHS	Both	45	9	
		Brockfield	NHS	Both	70	14	
		Kneesworth House	independent	Both	84	17	
		St John's House	independent	Both	32	6	
London	8	John Howard Centre	NHS	Both	117	23	
		North London Forensic Service	NHS	Both	141	28	
		The Orchard	NHS	Female	45	9	
		North London Clinic	independent	Male	42	8	
South East	6	Bracton Centre	NHS	Both	70	14	
		Amber Lodge	NHS	Both	64	13	
		The Dene	independent	Female	52	10	
South Central	5	Oxford Clinic	NHS	Both	58	12	
		Chadwick Lodge	Independent	Both	52	10	
South West	2	Fromeside	NHS	Both	80	16	
Totals	**57**	**26 (16 NHS, 10 independent)**			**1973**	**365**	**30**

In order to use research time efficiently, we have devised a sampling strategy by unit rather than by patient. There are currently approximately 57 units in England providing medium secure care in the 10 strategic health authorities (regions), 34 within the NHS and 23 in the independent sector. Following stratification by region and sector, one MSU has been included in regions with 1 to 3 units, 2 in regions with 4 or 5 units, 3 in regions with 6 or 7 units, 4 in regions with 8 or 9 units and 5 in one region with 10 MSUs. Units were drawn according to sector, geographical region, size and specialisation (eg. patient groups and designated purpose such as treatment, rehabilitation, etc.) with oversampling of units specialising in particular patient groups, including women and patients with learning disabilities. Our sampling strategy resulted in the inclusion of 26 MSUs overall, 16 NHS and 10 independent units, providing care for just under 2000 patients (see Table 2 – overall patient figures are based on preliminary data collection in preparation for this application, long-stay figures on estimates based on the assumption that 20% of patient will fall within this category). Contact details for selected units have been identified and willingness to participate has mostly been established. Notably the medical directors of all three

high secure hospitals and of the two largest independent medium secure providers (accounting for all but two of the sampled independent MSUs) have confirmed participation in the event of this application being successful. A trial of the data collection schedule has confirmed that the data required is readily available.

Data collection

For each patient resident in the identified units on the census date we will ask the contact person to supply the following information in anonymised form:

- Date of birth
- Gender
- Ethnicity
- Date of admission
- Admission source
- Mental Health Act section
- Type of current ward

Additional clinical and risk data and information on previous admissions to secure care will be collected if available. At the very least we will additionally collect data on the ward specifications of the units surveyed. As forensic care is provided according to clinical and risk profiles (e.g. wards designated to cater for patients with a particular diagnosis or level of risk), this will allow us to gain some further insight into patient characteristics and service provision.

Data analysis:

We will provide LoS profiles for high and medium secure services and identify how many patients have been resident in high or medium secure care for excessive amounts of time using simple descriptive statistics applying the definitions for long-stay described above.

Workpackage 2: Characteristics and needs of long stay patients (months 7 – 22)

In order to identify characteristics of long-stay patients and factors associated with risk of prolonged stay, we will collect in-depth clinical, offending and risk data and conduct an analysis of care pathways and needs of long-stay patients using file reviews and interviews with patients' Responsible Clinicians (RCs). Where this is not possible, we will send questionnaires to RCs instead of interviewing them. We will develop a categorisation of long-stay patients identifying groups with different need profiles.

Sample:

The total sample of long-stay patients in the units selected is expected to be around 120 in high secure and 380 in medium secure care. They will form the sample for WP 2. Due to our sampling strategy this sample is thought to be representative of the long-stay population in England. As individual RCs will potentially be responsible for the care of more than one long-stay patient, it is expected that the number of RCs to be interviewed will be about a third of the sample size.

Data collection:

Date will be collected over a 1 year period starting in August 2013. In order to maintain anonymity, data will be collected by unit staff (e.g. trainee doctors, audit department staff, research nurses, but also MHRN CSOs where relevant local arrangements have been made to that effect). Where this is not possible, date will be collected by our research staff in which case we will seek individual patient consent. The data collection tool will be piloted in patients in different level of security and within both NHS and private provider units. All individuals involved in this data collection will be be fully trained on the data collection schedule. Supervision from the principal investigator will be available and a number of records will be double-rated to ensure reliability of data extraction. It is expected that data collection will take one day per patient. It is expected that the majority of data will be readily available from the patient records. Some data (incidents, seclusion episodes) might be recorded in hospital wide registers simplifying data collection. Interviews with all RCs for the long-stay patients

identified will be conducted for clarification of data obtained from file notes and a more in-depth understanding of patients' mental health, psychosocial and service needs and reasons for long-stay.

Data to be collected from file review will include:

- Start date of continuous medium or high secure care
- Movements between forensic services and within institutions since continuous admission to high or medium secure care
- Clinical diagnosis, including substance misuse and personality disorders
- Offending history including index offence, using a list of pre-defined offence categories in accordance with those used in the Police National Computer database
- Current risk, using the HCR-20 [28], the most widely used and routinely recorded risk assessment instrument in forensic care in the UK
- Violent incidents and episodes of seclusion since admission; change in frequency of these events over time (annual plotting)
- Treatment started and completed and timing of those interventions (an assessment of the overall appropriateness of interventions offered will be made by the research team)
- Meaningful contact with family or other significant contacts outside the clinical team
- Any referrals since admission to other psychiatric institutions and outcome
- Any Mental Health Review Tribunals and outcome

- RC interviews will capture: Security, dependency, treatment and political needs using a visual analogue scale developed by Shaw et al. (2010). The scale captures risk of violence and absconding, level of functioning, daily living skills, physical health needs, coping skills, insight, compliance, characteristics of 'high profile' status
- RCs view on level of security needed at present, in two and in five years' time
- RCs view on future service, including placement needs
- RCs view on need for life-long secure care
- Current problems preventing transfer or discharge

Data analysis:
Descriptive data on the long-stay patient group will be reported. Cross-tabulation will be used to establish absolute and relative frequencies for categorical variables. Means and standard deviations will be calculated for continuously distributed variables. Data transformation or non-parametric tests will be considered if examination of variables suggests non-normal distribution. We will identify potential risk factors for long stay using comparisons between subgroups stratified according to LoS. Chi-square and association tests will be applied to identify differences between patients according to security need and consultants' views on need for life-long secure care. We will use binary logistic regression to explore whether any of the factors identified from the literature and our own work predict consultants' view on level of security needed or need for life-long secure care. Milestones in patients' pathways (transition, completion of treatment, etc.) will be mapped onto pathway diagrams, recording number of patients taking each step and timing of steps. Incident data over time will be analysed using repeated measures ANOVAs. These data will allow us to further explore reasons for long stay, potential categorisation of long-stay patients and potential early indicators of non-progression. We will explore whether long-stay patients can be categorised into distinct groups with potentially different needs using structural equation modelling.

Work package 3: Patient experience of long-stay (months 19 – 30)

This WP will use qualitative interviews to identify patients' perspectives on long-stay including experience of treatment pathways and strengths and weaknesses of current service provision with a view of extrapolating key characteristics of acceptable long-term services.

Sample:

Patients identified as long-stay from both high and medium settings will be interviewed. A sampling frame will be developed including gender, current location and category of long-stay. Purposive sampling will be used to select participants representing different relevant criteria of the sampling frame. If a selected individuals does not wish to participate another individual with the relevant characteristics will be selected. Number of interviews will depend on data saturation; for the financial part of this application we have used the total figure of 30 for calculations.

Data collection:
A semi-structured approach will be adopted using topic lists drafted after literature review and in collaboration with service user representatives and refined progressively during the fieldwork. Key topics of the case-focused interviews are likely to include strengths, weaknesses and gaps of current service provision, experience of treatment pathways, perceived reasons for long-stay and long-term needs, the potential impact of the concept of long-stay units and quality of life. The interviews will be conducted by trained service users, supervised by the researcher attached to this WP in order to maximise respondents' engagement. Respondents will be asked questions that explore all topics set out in the pre-defined topic list. However, the researcher is free to vary the order and wording of questions (for the purpose of rapport and clarity of meaning to the respondent), will be required to also use probes and follow-up questions (to achieve the necessary depth and self-reflection on the part of the respondent), and be responsive to issues emerging from respondents' accounts. All interviews will be tape recorded and verbatim transcripts made. Informed consent will be sought from all participants.

Data analysis:
Interview transcripts will be downloaded to NVivo - a computer package for the management, classification and analysis of text-based data (QSR International, 2008). Using NVivo, thematic coding frameworks will be constructed which allocates codes to themes and issues emerging from the data, thereby facilitating the identification and organisation of emergent themes and issues.

The coding frameworks will be developed by the research assistant (RA) with support from Dr Weaver (TW). After coding by the RA, a sample of transcripts will be independently re-coded by a second researcher (TW) who will be blind to the original coding. This will enable discrepancies to be identified and consensus reached about the interpretation and application of the coding framework. Any data that do not fit the coding framework will lead to the generation of new themes and revision of the framework. Using this coding framework, data will be classified, indexed and subject to thematic analyses. The framework will facilitate the identification and organisation of key themes and issues in a consistent manner.

Work package 4: Service innovation (months 1 – 33)

This work package will use qualitative and quantitative methods to describe existing service models for long-stay secure forensic-psychiatric care internationally, develop potential service models for the UK context, explore the views of key stakeholders on such models, identify hindrances to their implementation and make recommendations regarding service innovation and future evaluation of such services.

International service models:
Based on (a) a review of the international literature, (b) interviews with senior managers of long-stay institutions outside the UK to be conducted alongside the 2013 Special Interest Group meeting at the annual conference of the IAFMHS, and (c) contacts with our international advisors from the Netherlands and Germany, we will describe service models of long-stay forensic care in the Netherlands and Germany (and in other countries should they become available throughout the lifetime of this project). Semi-structured interviews will cover key characteristics and good practice of service provision, key challenges and hindrances in their implementation, and outcomes. Information about practical aspects of such services (e.g. size of wards, level of security) as well as clinical, risk and pathway information will be obtained via interviews and written material on available units.
UK expert interviews:
Expert interviews will be conducted with

(a) senior commissioners and policy makers
We will interview senior commissioners and civil servants within the Department of Health and Ministry of Justice, using purposive sampling. We are aware that there are likely to be changes within these structures following the new Health and Social Care Bill and we will keep these developments under close review. The purpose of these interviews is to identify interviewees' perception of the problem of long-term secure forensic care, possible strategies to address this issue and factors which may impact upon the development and implementation of a strategy for the management of long-stay forensic-psychiatric patients. International service models will be presented with a view of obtaining interviewees' views on the applicability to the UK context. We have already begun to identify some individuals to be interviewed and expect the total number to be around 10.

(b) senior clinicians in high and medium secure settings
We will interview senior clinicians responsible for the care of long-stay patients in high and medium secure care. Interviewees will be selected randomly from those interviewed in WP 2 and it is expected that these interviews can take place alongside those inquiring about patient-specific information. Interviews will cover interviewees' experience with the care of long-stay patients, challenges in current service provision for this group, their views on potential new service models and any resistance to new ways of working with these patients. Total number of interviews will be around 20 depending on data saturation.
All interviews will be recorded verbatim with the consent of the interviewee, transcribed and analysed using NVivo similar to the process described in WP 3.

Workshops:
In year 2 we will conduct a series of workshops over a 2 day period covering a range of themes relevant to this proposal. We will invite stakeholders from various backgrounds, including policy makers, commissioners, senior managers, members of MHRT panels and clinicians (including psychiatrists, nurses, social workers and OTs). Members of the Service User Group and Project Advisory Group will also attend. The purpose of these workshops is to explore some pertinent issues in more detail in smaller groups. The selection of topics will be guided by the preliminary work of the project but they are likely to include: ethical issues, legal issues (including the role of MHRTs in long-stay), applicability of service models from non-UK settings, service developments for long-stay forensic patients within the UK, possible future service models, hindrances to the implementation of long-stay services, quality of life, service user perspectives, etc. We will take detailed notes of the discussions which will be used in the preparation of the report on service models and recommendations for implementation.

Delphi exercise:
A formal consensus method (Dephi) will be used to agree essential and desirable elements of long-stay forensic psychiatric care in the UK context. The study will be conducted electronically. We will include 150 experts from a range of backgrounds, including commissioners, senior managers, forensic psychiatrists, psychologists, nurses, social workers and OTs. In round 1 participants will be asked to describe the features of an appropriate service for long-stay patients in secure forensic settings, first generally and then in relation to specific prompts (e.g. level of security, quality of life, therapeutic interventions and other activities, etc.). Data from Round 1 will be collated into a list of items for Round 2. Participants will be asked to rate their agreement with each item. Items that have > 80% agreement will be used in the final recommendations from this project.

Development of potential UK service models
Information obtained in the previous elements of this project will be drawn together to develop potential service models for the UK context .This will include in particular:

- An assessment of differences in funding, service delivery, governance, legal frameworks and patient populations between the UK and the Netherlands and Germany
- An assessment of service specifications of long-stay care in these two countries against UK national policy and guidance with a view of evaluating which of these elements could be realised in the UK context

- A description of potential UK service models based on needs of long-stay patients alongside an assessment of probably cost for such services compared to current costs (cost-analysis) based on the current long-stay forensic population within Nottinghamshire NHS Trust
- A model business case for the development of such a service within Nottinghamshire NHS Trust including an exploration of potential obstacles in the implementation of such development

Contribution to collective research effort and research utilisation:

The proposed project contributes to the collective NHS research endeavour in a number of ways. It addresses an area of weakness in UK research, that into mental ill health. It focuses on a doubly stigmatised patient group, those with mental disorders and offending behaviour. Little NIHR funding has been dedicated to this group, specifically none studying service provision for populations in high and medium secure care, despite the apparent financial and ethical challenges in the care of this population. This project involves collaboration between researches, NHS managers and service users. Stakeholder involvement is planned throughout the project to ensure ongoing information to relevant policy makers and commissioners without delay and to steer the research. The Project Advisory Group will further strengthen collaboration between policy makers, commissioners, managers, clinicians, researchers and service users and expedite the utilisation of findings.

The following specific outputs will be produced:

WP 1:

- Length of stay profiles of the current high and medium secure patient population
- Estimated numbers of long-stay patients in England

WP 2:

- Risk factors for long-stay
- Categories of long-stay patients with estimated current numbers in each category in England and their location (high or medium secure care)
- Checklist for categorisation of long-stay patients according to patient and non-patient factors and long-term need

The findings of these two work packages will provide vital information on the current long-stay forensic-psychiatric population and their needs which will aid policy makers, commissioners and managers in the development of a strategy for appropriate and sustainable service provision for this patient group. It will help to target the expensive resource of high and medium secure forensic-psychiatric care at those who actually require such intensive input and benefit from it.

WP 3:

- Detailed description of patients' experience of long-stay and key considerations for the development of long-stay units from the user perspective

WP 4:

- Report on long-stay services internationally, in particular the Netherlands and Germany, including an assessment of differences in funding, service delivery, governance, legal frameworks, national policies, and patient populations compared to the UK
- Description of potential UK service models for long-stay forensic populations and an assessment of their probably cost compared to current service provision (cost-analysis),
- , Key recommendations for implementation, including how to overcome hindrances in such implementation (e.g. legal challenges, resistance to new ways of working)
- A model business case for the development of such a service within Nottinghamshire NHS Trust including an exploration of potential obstacles in the implementation of such development
- Recommendations for future evaluation of long-stay services, including outcome and long-term economic evaluations (cost-effectiveness and cost-utility analysis)

- Recommendations regarding future research priorities in relation to the population of this proposal

Specific dissemination will be targeted at particular groups, including policy makers, commissioners, senior managers, clinicians, researchers, voluntary sector organisations, service users and carers. Reports will be produced at end of year 1 and 2 in addition to the final research report. Briefings will be produced from these reports to suit the needs of the various recipients of this dissemination plan. We will use the relevant Mental Health Research Network and the NIHR network as additional vehicles to disseminate findings using research digests. Service user involvement will ensure the research is disseminated through relevant patient groups. Involvement of international colleagues will promote international impact. Papers for peer reviewed academic journals and conferences will be prepared.

An end of project conference will be organised presenting the findings to all relevant stakeholders.

Plan of investigation and timetable

A full breakdown month by month of the project activities and milestones is provided in the attached Gantt chart which is copied below in slightly abbreviated form. We aim to have Section 251 approval in place before the start of the project while NHS Ethics for WP 3 will be sought during the lifetime of this project.

Project month	1	2	3	4	5	6	7	8	9	10	11	12
Project Timeline	Jan-13	Feb-13	Mar-13	Apr-13	May-13	Jun-13	Jul-13	Aug-13	Sep-13	Oct-13	Nov-13	Dec-13
PROJECT ACTIVITIES BY WORKPACKAGE												
WP 1 - Length of stay												
Confirm contacts												
Data collection												
Data analysis						End						
WP 2 - Characteristics and needs												
Identify long-stay cohort												
Devise schedule visits												
Case file reviews												
Consultant interviews												
WP 4 - Service innovation												
Expert interviews internationally												
Collation of information on long-stay services								Re-port				
Expert interviews commissioners, policy makers												
Analysis expert interviews												

Project month	13	14	15	16	17	18	19	20	21	22	23	24
Project Timeline	Jan-14	Feb-14	Mar-14	Apr-14	May-14	Jun-14	Jul-14	Aug-14	Sep-14	Oct-14	Nov-14	Dec-14
WP 2 - Characteristics and needs												
Case file reviews, ctd												
Consultant interviews												

Data analysis										End		
WP 3 - Patient experience												
Apply Ethics						Appr						
Devise interview schedules												
Organisation interviews												
Patient interviews												
WP 4 - Service innovation												
Senior clinician interviews												
Analysis interviews												
Prepare workshops												
Conduct workshops												
Analyse workshops												

Project month	**25**	**26**	**27**	**28**	**29**	**30**	**31**	**32**	**33**	**34**	**35**	**36**
Project Timeline	**Jan-15**	**Feb-15**	**Mar-15**	**Apr-15**	**May-15**	**Jun-15**	**Jul-15**	**Aug-15**	**Sep-15**	**Oct-15**	**Nov-15**	**Dec-15**
WP 3 - Patient experience												
Transcribing interviews												
Analysis interviews						End						
WP 4 - Service innovation												
Prepare Delphi exercise												
Conduct Delphi exercise												
Analysis Delphi									End			

Approval by ethics committees:

We recognise that psychiatric inpatients are a vulnerable group of individuals, in particular those with offending histories who are detained in highly restrictive secure settings. The highest level of scrutiny therefore has to be applied to data held on such individuals and they should not feel under any pressure to participate in research. It will be necessary for staff appointed with direct contact with such service users to have sufficient clinical experience to deal sensibly with this patient group. WP 1 and 2 are service evaluation and as such do not require approval by an Ethics Committee.

For WP 2 we originally planned to seek approval by the National Information Governance Board under Section 251 of the NHS Act 2006 to collect relevant data and review patient files for information on sociodemographics, clinical, risk and pathway information without individual patient consent. The rigorous evaluation of determinants of long-stay forensic-psychiatric care for a group of individuals who pose a risk to the public and whose management is particularly resource intensive is important and it is ethically proper that the refusal of individuals to participate in such an evaluation does not risk compromising the representative nature of the study. However, following discussions with relevant individuals, it was felt that NIGB approval was not feasible to obtain for this study. We have therefore devised a new procedure for data collection for WP2 so that the data will be collected from within the units and be provided to the research team in fully anonymised form. Where this is not possible, we will seek patient consent for the review of their files

For WP 3 NHS Research Ethics Committee approval will be obtained and R&D approval will also be sought from participating organisations via the CSP process. It will not be possible to obtain this before the start of the project as patient interview numbers / location will only be available following WP 1. Full informed consent

will be obtained from all patients participating in research interviews. They may withdraw their consent at any time.

Project management:

Overall project management will be provided within the Institute of Mental Health (IMH), a collaboration between the University of Nottingham and Nottinghamshire Healthcare Trust, attracting some £6 million in research funding annually. The IMH will provide project management and financial and risk management support.

The project management team will meet quarterly and be comprised of

- Project manager – Gerry Carton, Associate Director IMH
- The lead applicant (also lead for WP 2)
- The leads for WPs 1, 3 and 4 (VF, TW and RMcD)
- Research Management and Governance Support – Shirley Mitchell, Head of Research Management and Governance, Nottinghamshire Healthcare NHS Trust
- Finance/Risk Management Specialist – Lesia Nel, Research Project Co-ordinator, Institute of Mental Health
- Finance Support – Diane King, Finance Administrator, Nottingham Healthcare NHS Trust

The project management team will have access to dedicated administrative support.

Clear reporting lines have been established. A gantt chart has been drawn up clearly identifying timelines and deliverables. The WP leads will be responsible for their deliverables and will report to the project manager. Any slippage in milestones will be identified immediately so that remedial action can be taken.

The lead applicant will be responsible for applying for NIGB and IRAS approvals. The lead institution will be responsible for recruitment and supervision of one of the two research assistants while the second one will be managed within Imperial College London and supervised by TW.

A Project Advisory Group has been established to provide a wider perspective on the research. The group will comprise of the project manager and WP leads and the following external experts:

- Nick Benefield, Head of National Personality Disorder Programme, Department of Health
- Dr Peter Braun, Lead Psychologist, Long stay forensic psychiatric care unit, Pompe Foundation, The Netherlands, via videolink
- Dr Graham Durcan, Associate Director, Centre for Mental Health
- Dr Paul Gilluley, Consultant Forensic Psychiatrist, Chair of the Quality Network Advisory Group Medium Secure Care
- Dr Quazi Haque, Executive Medical Director, Partnerships in Care
- Dr Lawrence Jones, Lead Psychologist, Dangerous and Severe Personality Disorder Service, Rampton Hospital
- Kath Murphy, Secure Policy/Specialised Mental Health Transitions Lead, Department of Health
- Dr Rüdiger Müller-Isberner, Medical Director, Haina Forensic Psychiatric Hospital, Germany, via videolink
- Ruth Sargant, Head of East Midlands Specialised Commissioning Mental Health and Learning Disability
- Two service users from the Service User Reference Group

The Project Advisory Group will meet bi-annually with the first meeting in month one of the project.

PPI:

Input to the design of this proposal was provided by the Peaks Unit (a service for patients with severe personality disorders) Patient User Group (PUG), Rampton Hospital, and a Service User Champion, NG, with experience in medium secure care who now resides in the community. Presentations to the PUG and NG have helped shaping the overall study design by examining the appropriateness and relevance of the proposal for patients in secure forensic settings. It was felt that this proposal was highly relevant and had the potential to promote service innovation to the benefit of patients. We received constructive feedback on some elements of the proposal, in particular patient interviews and wording of the research summary for ease of comprehension. Suggestions were also made regarding the ways in which the researchers could collaborate with service users throughout the conduct of this project and these are reflected in the PPI involvement plans.

The PPI element of this project will be led by co-applicant JR who has the relevant experience and expertise to ensure patients and carers are fully involved in the running of this project. Nottinghamshire NHS Trust has clear policies to support service user involvement in research, including payment for such involvement. This project will make use of as well as strengthen the structures already in place to facilitate service user involvement to ensure acceptability and applicability of research findings. JR have recently established a Forensic Service User Research Group who are currently undergoing training on aspects of their role, including on study design, strategies for accessing patients, language used in participant information and consent forms, data collection, analysis and dissemination. Five individuals of this group will form our Service User Reference Group to inform the ongoing development and implementation of the research. This group will meet quarterly and will be supported in their role by JR. Two members of the Service User Reference Group will sit on the Project Advisory Group to convey the views and suggestions of the Service User Reference Group. In addition to these formal opportunities for input, we will seek their advice whenever required. It is envisaged that their contribution will be particularly valuable in the preparation of participant information sheets, design of patient interview schedules, recruitment and interviewing of patients, analysis of qualitative patient interviews, development of service innovations and dissemination of findings. Members of the Service User Reference Group will be paid according to the Nottinghamshire Healthcare NHS Trust service user and carer payment policy.

Expertise and justification of support required:

Expertise:
The research team has the breadth of experience and expertise necessary to deliver this project. Some of the applicants (BV, JR, TW, JC, CD) have already successfully worked on other projects, e.g. Ministry of Justice commissioned work on the evaluation of the new personality disorder strategy and an NIHR Programme Development Grant. The team has a track record of published work relevant to this project and is experienced in managing research.

BV is a clinical academic and consultant forensic psychiatrist experienced in service provision at different levels of security. BV currently works in the Dangerous and Severe Personality Disorders service which caters for individuals with complex and long-term needs. She is a member of the Special Interest Group of the International Association of Forensic Mental Health Services on long-term care and has personal experience of service models for long term care in other countries. BV will be responsible for the overall running of the project, ethical applications, supervision of some of the junior staff, writing of the final report and communication of findings to clinicians, managers, commissioners and policy makers. She will lead WP 2.

TW, Imperial College, London, is a social scientist and PI on health services research projects with a track record in design and management of multi-method evaluative research investigating organisation and delivery of services. Imperial College London has an international reputation for mental health services research and close links with Central and North West London NHS Foundation Trust and West London Mental Health Trust (including Broadmoor Hospital). TW will lead WP 3, including supervision of junior staff attached to this WP.

JR is Associate Professor of Mental Health Nursing and the Trust lead for Recovery. She is the service user engagement fellow for CLAHRC-NDL and chair of the national MHRN Carer research group. She has

experience of working collaboratively with service users and carers in research and has published widely on the subject. She sits on various Service User and Carer research committees and will coordinate the service user involvement element of the project.

JC is Director of Forensic Research at the Wolfson Institute of Preventive Medicine at Queen Mary, University of London. He has a track record in epidemiology and health services evaluation, including surveys of medium secure services and the Prisoner Cohort Study. He will provide input into the sampling and data collection strategy and advice on the overall management of the project.

Ruth McDonald is Professor in Healthcare Innovation and Learning with a particular interest in change and resistance in health care organisations and Director of the Executive Healthcare MBA. She has widely published on change, performance and economic evaluations in health care institutions and will lead WP 4 addressing the translation of study findings into practice.

Peter Bartlett is Professor in Mental Health Law with a particular interest in involuntary treatment, international comparison of mental health law and ethical issues in forensic-psychiatric care. He will contribute to WP 4, focusing on ethical and legal issue of long-term care in secure forensic settings.

Mike Harris is an experienced manager of forensic psychiatric services at all levels of security within Nottinghamshire Healthcare NHS Trust, the largest provider of secure hospital forensic care in the country. He will ensure findings are translated into practice through innovation of service delivery.

Conor Duggan is emeritus professor in forensic psychiatry at the University of Nottingham and current R & D lead of the largest provider of independent medium secure care, Partnerships in Care. CD has outstanding expertise in personality disorder research and outcome research in forensic psychiatric settings and has pioneered forensic services for personality disordered offenders.

Eddie Kane is the Director of the Centre of Health and Justice in the Institute of Mental Health; he will provide support in the implementation of the findings of this research and contacts to policy makers.

VF is an experienced psychiatrist, already holding a CCT in Old Age psychiatry and currently training in forensic psychiatry as an Academic Clinical Fellow. He has a Masters degree in Health Policy, Planning and Financing. VF has completed the preliminary work for the project. He will lead on WP 1 and will contribute to the data collection of WP 2.

Two research assistants will be appointed, one supporting WP 1 and 2 and one for WP 3; both RAs will contribute to some elements of WP 4. RA 1 will be employed for the entire duration of the project, RA 2 for part of yr 2 and yr 3 only.

A named statistician (Min Yang) with experience in epidemiological research in forensic settings has been identified who will provide sessional statistical support.

<u>Justification of support:</u>
Most costs will be attracted for staff as outlined above. Costs have been calculated to provide value for money and to keep staff costs to a minimum without jeopardising the quality of the research.

Direct costs:
WP 2 will attract costs for travel, accommodation and subsistence during data collection as sites are spread across England. We will maximise data collection on each site by completing one site at a time, staying for several days or weeks as required. We have calculated an average of £50 for one-way travel to the sites. Researchers will stay in local B&Bs during data collection although we expect a number of sites will be able to support the research through provision of hospital accommodation. We have calculated £50 for overnight stay

in B&Bs per day and £20 for meals. If data collection takes more than one week at one site, researchers will travel back at the end of the week and return in the next week.
WP 3 will again involve travel to a variety of sites for patient interviews albeit on a much smaller scale (approx. 30 participants).
For WP 4 10 experts (commissioners, policy makers) will be interviewed and travel costs are required for this.

Further direct costs include Project Advisory Group meetings (travel expenses), conference attendance for dissemination of findings (Royal College of Psychiatrists Forensic Faculty in yr 2 and 3; International Association for Forensic Mental Health Services [IAFMHS] in yr 1 and 3 for one person each; the IAFMHS conference in yr 1 will also used for interviews with international experts), costs for workshops in yr 2 and the end of project conference (only catering, venue will be provided free of charge by Nottinghamshire NHS Healthcare Trust).
Service user involvement is an important element of this project. Support will be required for service user group meetings, reimbursement according to the Nottinghamshire NHS Healthcare Trust service user and carer payment policy and childcare during attendance at meetings. We also involve service users in conducting patient interviews and their time will be reimbursed at £100 / day.
Patients participating in the qualitative interviews of WP3 will be paid an inconvenience allowance of £10 / interview.
Other direct costs include assistance with data collection by medical records staff for WP 1 and interviews with patients' Responsible Clinicians (WP 2 and 4).
Only minimal costs are required for equipment (e.g. 2 laptops).

Indirect costs:
Indirect costs include HEI indirect costs.

NHS support costs:
NHS support costs include assistance in the recruitment of patients for WP 3 (ie asking patients whether they are willing to be approached by the researcher – to be conducted by nursing staff). We have received agreement in principle from a substantial majority for CLRNs already to support these costs.

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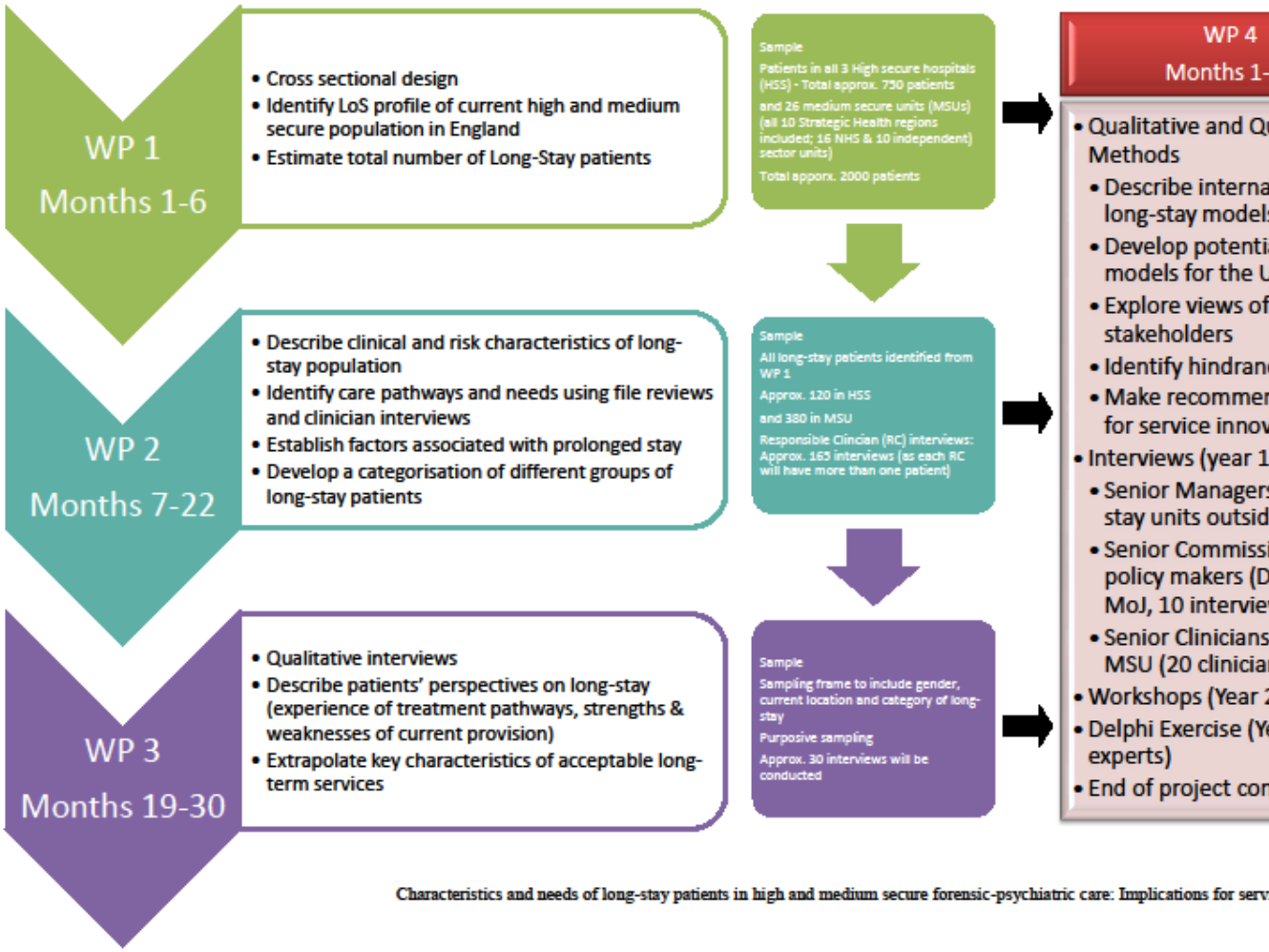
Flow chart



Characteristics and needs of long-stay patients in high and medium secure forensic-psychiatric care: Implications for serv