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National Collaborative Commissioning Unit

Improving Care, Improving Lives

Chief Nursing Officer's National Care Review of Learning Disabilities Hospital Inpatient Provision Managed or Commissioned by NHS Wales

SHANE MILLS, MARTYN FRENCH & ADRIAN CLARKE – FEBRUARY 2020

This National Care Review has been commissioned by Professor Jean White, Chief Nursing Officer, Welsh Government, as part of the Welsh Government Learning Disability – Improving Lives Programme from the NHS Wales National Collaborative Commissioning Unit.

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- Patients on the units reviewed who offered their opinions.
- Staff on the units reviewed who offered their time and support.
- Mr Joe Powell, Chief Executive of All Wales People First, for his advice and support.

Foreword

I commend the publication of this much-needed and comprehensive 'Improving Care, Improving Lives' Review, which highlights key issues about the care and treatment of people who are inpatients in learning disability hospitals. It is concerning, given the aspiration and transformational nature of the 'All Wales Mental Handicap Strategy' of 1983 and current legislation, such as the Social Services and Well Being (Wales) Act and the Well Being of Future Generations (Wales) Act, that we still deem it acceptable to house some people with learning disabilities within the hospital system, when it is no longer appropriate. If this situation is not remedied, we cannot truly claim that we have eradicated the unjust and deficit-centred culture of the long-stay institutions of the past.

It is concerning to see within the review the high prevalence of use of medication amongst those who display behaviour that challenges. It is concerning too, that many people prescribed medications are not diagnosed with any form of mental illness. This medication is not only inappropriate, it reinforces a negative attitude that learning disability is a medical condition that needs to be controlled with drugs. It would not be acceptable for any citizen who is not sick to be housed in a hospital setting; why then is it still acceptable in the twenty-first century to house some people with learning disabilities in hospitals years after they were originally admitted?

We have made much progress in the way we support people with learning disabilities, but there is still a long way to go. Most people with learning disabilities live in an appropriate community setting, have person-centred support and work with services in a co-productive way. Although things aren't perfect, we are recognising that improvements have been made and more still need to be made. It seems, however, that some people with learning disabilities in health settings have been forgotten and excluded in our high aspirations for the future. People who could realistically be living in the community, making an active and positive contribution to Welsh society and achieving personal well-being, are potentially stuck in institutions which are supposed to aid them to move on with their life.

I call for this Review to kick-start a national conversation about this issue and for all agencies in Wales to work with the Welsh Government to remedy this breach of basic human rights for patients with learning disabilities in our hospitals. It is important that we take a different approach to behaviour that challenges and to recognise when people are ready to move into mainstream society. That we aim to understand and support people with learning disabilities appropriately and to prevent crisis where we can. That we don't fall into the trap of mistaking 'challenging behaviour' as 'bad behaviour'. That we don't contain or restrain any citizen inappropriately. It is important that community and citizenship is achievable and attainable for all. It's time to put the humanity back into all our human services.

Joe

Joe Powell, Chief Executive, All Wales People First.

All Wales People First is the united voice of self advocacy groups and people with learning disabilities in Wales.

National Ca
NUM

26,364

PIECES OF INFORMATION

on patient care were gathered for this National Care Review

PATIENT GENDER

Male 69% Female 31%

AVERAGE AGE

of patient Male 42 Female 45

PATIENT CHALLENGES

77% of patients exhibiting one or more **behaviours that challenge** within the **previous ninety days**

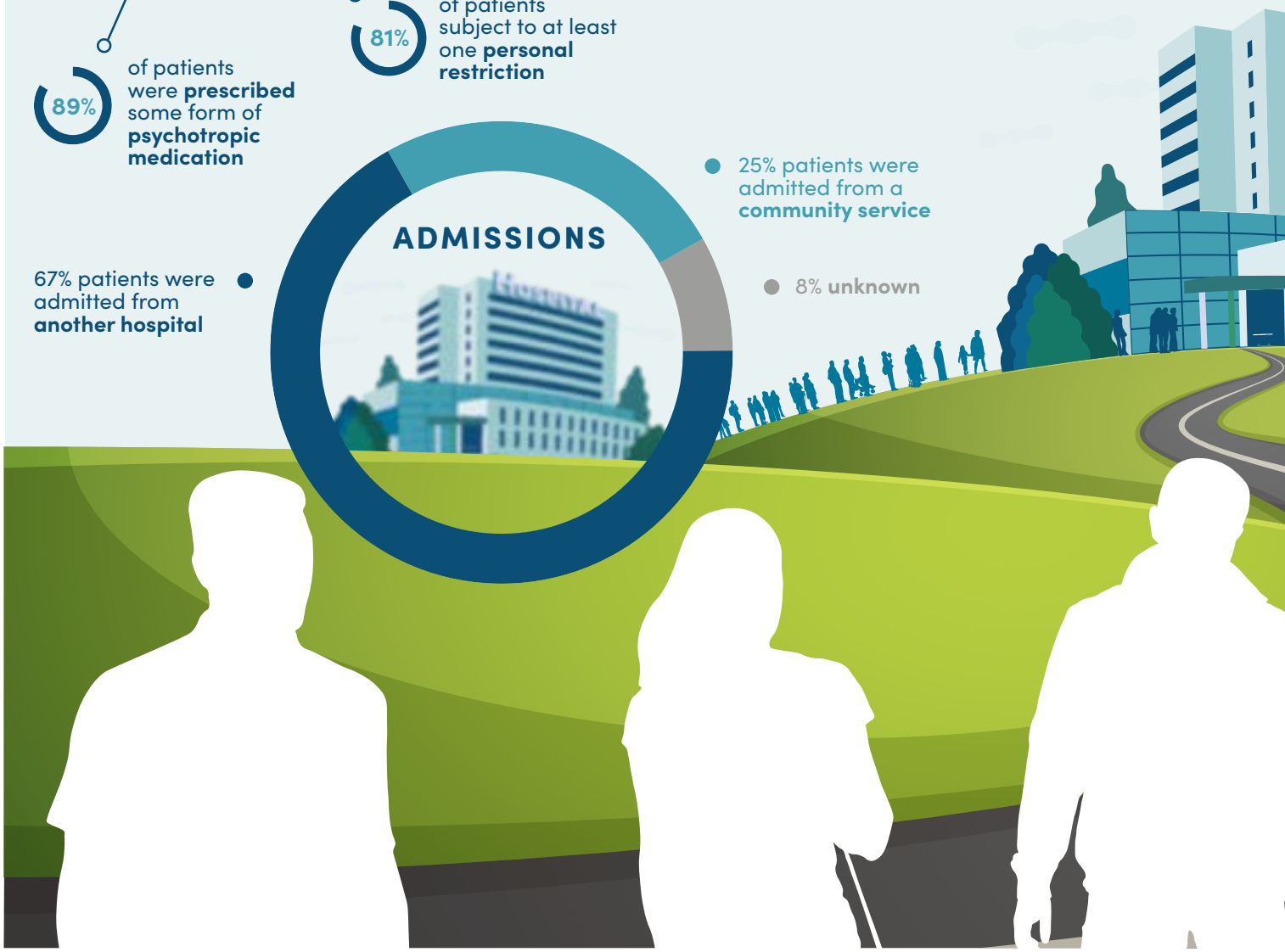
36% of patients subject to one or more **restrictive interventions** within the **previous ninety days**

81% of patients subject to at least one **personal restriction**

89% of patients were **prescribed** some form of **psychotropic medication**

ADMISSIONS

- 67% patients were admitted from **another hospital**
- 25% patients were admitted from a **community service**
- 8% **unknown**



PRIMARY DIAGNOSIS

- 87% **learning disabilities**
- 7% **autistic spectrum disorder**
- 7% **mental illness**

AVERAGE LENGTH OF ADMISSION

Male: **4.9 years**

Female: **5.8 years**

re Review in BERS

PATIENT SUPPORT

84% of patients were assigned a **care coordinator**

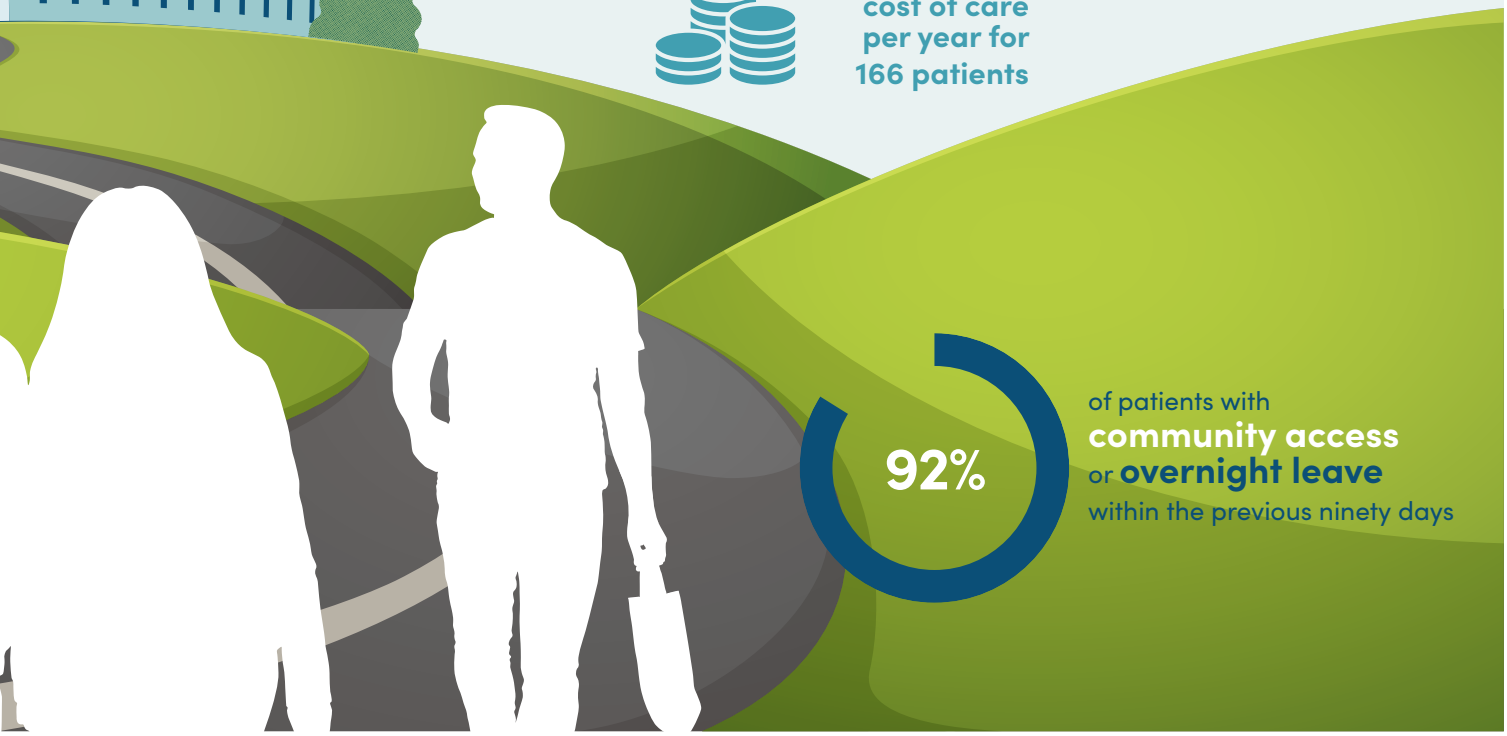
78% of patients had a **formal care plan**

100% of patients had a **hospital support plan**

Total number of dedicated hours being delivered a day 884

£33.5 MILLION

cost of care per year for 166 patients



92%

of patients with **community access** or **overnight leave** within the previous ninety days

Notes and considerations

Terms: 'Learning disability' is used as a term within this Review to describe individuals with a clinical diagnosis of intellectual disability. 'Learning disability' is known by a number of terms which are often used interchangeably. The UK government uses the term 'learning disability'[1] whilst the Diagnostic and Statistical Manual of Mental Disorders version V use the term 'intellectual disability.'[2]

Validity: The information within this Review relates to circumstances and records available on the day of the audit. All audits were completed between February 2019 and June 2019, although follow-up questions and clarifications continued into November 2019.

Demographics: The information within this review relates to patients in hospitals caring for individuals with a diagnosis of learning disability. Those patients with a learning disability in hospitals caring for individuals with a diagnosis of mental illness are not covered in this National Care Review.

Data: There were 169 patients under the scope of this Review, although information for three of these individuals has been excluded from Parts B-E of this National Care Review. This exclusion is due to solitary patients being cared for in a specific provider type or there being only a single male or female in a specific type of provider, and our approach to minimise disclosure risks associated with small numbers. These exclusions are:

- The only patient cared for in a high secure hospital.
- The only female cared for in a medium secure hospital.
- The only female cared for in an uncontrolled egress hospital.

All percentages have been rounded. This means that for some figures the sum may not aggregate to 100%.

Patient Safety: All 169 patients included in this National Care Review had an individual report completed.

Any issues that immediately impacted on patient safety were raised with the provider on the day of audit.

People not Numbers: Whilst this National Care Review has many graphs and statistics, we note that behind every number is a vulnerable individual who deserves high quality and safe care.

Executive Summary

This National Care Review found no immediate safety concerns. However, it has highlighted a number of issues that need to be addressed urgently. This review found some areas of good practice and some services which function well, such as the assessment and treatment unit managed by Aneurin Bevan University Health Board.

This review found an aging patient cohort. We must ensure plans are in place, within the Welsh NHS, to support an aging and frail population including those patients with a learning disability. This review found that many patients with a learning disability have concurrent diagnoses such as dementia and autism and we must ensure that we have fit-for-purpose environments and trained, experienced staff to manage these complex presentations.

This review found patients with long lengths of stay, and many transferred between hospitals when alternatives could have been considered. To prevent this, we must take a 'community first' approach and avoid hospital being considered anyone's home.

This review found issue with some patients deprived of their liberty, and we must ensure that patients continue to consent being an inpatient, otherwise we must apply the full protection of the legal safeguards.

This review found that not all patients had a care plan in place, and that not all care plans had been regularly reviewed. We must ensure that the aims and objectives of every admission is clear and agreed between family, provider and care coordinator. The admission must be subject to regular review from the full multi-professional team with the patient, family and advocates at the centre of every care-planning meeting.

This review found high use of psychotropic medications and a scarcity of therapy staff, and we must ensure that pharmacological interventions are seen as one strand of a holistic approach which includes psychological, psychosocial, behavioural and occupational therapies. Prescribed medications must be monitored closely for efficacy and side effects, subject to regular review and prescribed at the minimal dosage for the shortest time.

This review found many occurrences of behaviours that challenge, and we must ensure that staff are empowered, trained and present in sufficient numbers to take a positive, patient-centred approach to prevent harm and maintain a therapeutic environment.

Restrictive interventions are sometimes required, and this review found many occasions where they had been applied. These interventions should always be used as a last resort and involve the minimum degree of force, for the briefest amount of time and with due consideration of the dignity and respect of the patient. Each and every occasion of the use of such interventions must be recorded, reviewed and reported. Health Boards must have mechanisms in place to monitor and reduce restrictive interventions.

This review found patients who had been in regular contact with primary and urgent

healthcare services and we must ensure that the physical well-being of patients is assessed, monitored and maintained.

This review found many, but not all, patients satisfied with their admission and feeling staff were supportive. Understanding and meeting patient expectations and listening and learning from their experiences must become the building blocks of efficient, effective and empowering services.

This review found a significant number of patients who may be considered for transition to the local community. Transition is a multifaceted, formidable and sometimes frightening process and requires careful planning with the patient, their carers and community services.

We should accelerate and expand the projects on-going in many Health Boards, of commissioning high-quality community placements for long-stay patients. Where these projects are not in place, they should be established as soon as possible.

Transitioning patients to community placements will enable resources to be reinvested in robust, responsive and preventive community services that will improve the care and lives of our patients.

Recommendations

This National Care Review makes 70 specific recommendations to be considered by providers and commissioners of care, as well as Welsh Government.

Providers

Recommendation 1. Providers should ensure that staff are aware of differences in presentation and need of male and female patients.

Recommendation 3. Providers should ensure that staff are trained to recognise and meet the needs of older persons with a learning disability.

Recommendation 11. Providers should ensure that all patients, not subject to detention under the Mental Health Act or to Deprivation of Liberty Safeguards, have the capacity to consent to being an inpatient.

Recommendation 12. Providers should ensure that all patients subject to detention under the Mental Health Act or to Deprivation of Liberty Safeguards are aware of their rights.

Recommendation 17. Providers should ensure that hospital support plans are reviewed regularly, within a maximum time period of three months.

Recommendation 19. Providers should ensure that all care plans and hospital support plans are developed with specific objectives, measurable outcomes and clear timescales.

Recommendation 22. Providers should ensure that the patient's outcomes are discussed as part of the care plan and hospital support plan reviews.

Recommendation 24. Providers should ensure that all medication is prescribed at the minimum dosage to alleviate the verified symptoms.

Recommendation 26. Providers should ensure that all medications are regularly reviewed for effectiveness and discontinued where efficacy is not demonstrated.

Recommendation 27. Providers must ensure that the patient, local care team and carers are involved in the decision to commence or discontinue any psychotropic medication.

Recommendation 28.	Providers should ensure that all patients prescribed psychotropic medication have a recognised side-effects monitoring tool completed.
Recommendation 29.	Providers should ensure that patients and families receive information, in an accessible format, on desired effects and possible side-effects of medication.
Recommendation 30.	Providers should record all incidents of behaviours that challenge.
Recommendation 31.	Providers should deliver a safe, effective and therapeutic environment of care, in order to reduce frustration and boredom which could lead to behaviours that challenge.
Recommendation 32.	Providers should ensure that staff are trained to recognise escalating behaviours and to deliver positive and preventative interventions.
Recommendation 34.	Providers must ensure that staff well-being is protected if they are regularly exposed to behaviours that challenge.
Recommendation 35.	Providers should ensure that any restrictive intervention involves the minimum degree of force, for the briefest amount of time and with due consideration of the self-respect, dignity, privacy, cultural values and individual needs of the patient.
Recommendation 36.	Providers should ensure that all incidents of restrictive interventions are recorded, reviewed and reported.
Recommendation 37.	Providers should ensure that any restrictive intervention is proportionate to the risk posed by the behaviour that challenges.
Recommendation 40.	Providers should ensure that the rationale for application and planned duration for any and all personal restrictions should be clearly documented in the patient's hospital support plan and be regularly reviewed.
Recommendation 42.	Providers should ensure that any dedicated support balances the risk to patients' safety with the promotion of dignity and independence.

Recommendation 43.	Providers should ensure that all patients are enabled and encouraged to access the local community safely.
Recommendation 44.	Providers should ensure that all patients have access to primary care services as and when required.
Recommendation 45.	Providers should ensure, where safe to do so, that attendance at urgent care services is prevented by pre-emptive interventions, staffing levels and staff training.
Recommendation 49.	Providers should undertake regular patient experience surveys in partnership with independent advocacy services and use the findings of these surveys to improve care.
Recommendation 51.	Providers should ensure that their environments of care are safe, high quality, fit for purpose and repaired and redecorated when necessary.
Recommendation 52.	Providers should ensure that patients have access to a 'patient's kitchen' and hot and cold drinks, after appropriate risk assessment.
Recommendation 54.	Providers should review, record and discuss the patients Level of Care on a monthly basis to support recording of progress.
Recommendation 56.	Providers should ensure that they regularly review and revise each unit's staffing requirements to ensure that the needs of patients are met.
Recommendation 58.	Providers should ensure that the patients have access to staff with specific skills, training and experience to enable them to achieve optimal functioning and well-being.
Recommendation 59.	Providers should ensure that staff are delivering high quality, evidence-based interventions to achieve the patients' outcomes.
Recommendation 60.	Providers should ensure that all patients are assessed for behaviour that indicates institutionalisation.
Recommendation 61.	Providers should ensure that the maintenance and promotion of self-advocacy, self-resilience and the reduction in dependency is a primary focus of care delivery.

Recommendation 65. Providers should ensure that patients and their families and carers are involved in developing and enacting the transition plan.

Recommendation 66. Providers should ensure that the transition plan is discussed and progressed by the unit staff and local care team at their regular meetings.

Commissioners

Recommendation 2. Commissioners should take account of the differences in the needs of male and female patients in the design and delivery of services.

Recommendation 4. Commissioners should ensure that they have planned learning disability services to take account of an aging population profile.

Recommendation 5. Commissioners should ensure that they have planned learning disability services to take account of patients with specific needs such as autistic spectrum disorders, dementia and mental illness.

Recommendation 6. Commissioners should ensure that staff are trained to recognise and meet the needs of patients with a learning disability that are concurrent with other conditions such as an autistic spectrum disorder, dementia and mental illness.

Recommendation 7. Commissioners should identify those individuals most at risk of being admitted to hospital, so that the right support can be made available to prevent the need for admission.

Recommendation 8. Commissioners should have clear pathways in place to promote a 'community first' approach and to minimise transfer of patients from one hospital to another.

Recommendation 9. Commissioners should ensure that no hospital bed is classed as an individual's home and every endeavour should be made to see community care as the 'default option' for all patients.

Recommendation 10. Commissioners should target resources at transitioning those patients in assessment & treatment units with a length of stay over one year, and those in other providers with a length of stay over five years.

Recommendation 13.	Commissioners should ensure that all patients subject to detention under the Mental Health Act or to Deprivation of Liberty Safeguards are subject to regular review.
Recommendation 14.	Commissioners should ensure that all patients in hospital are assigned a care coordinator.
Recommendation 15.	Commissioners should ensure that all care coordinators understand their role in ensuring the patient is cared for in a safe and high quality environment and in planning and expediting the patient's transition.
Recommendation 16.	Commissioners should ensure that care plans are reviewed regularly, within a maximum time period of six months.
Recommendation 18.	Commissioners should ensure that all care plans and hospital support plans are co-produced with the patient and with the involvement of the care coordinator and the patients' families.
Recommendation 20.	Commissioners should ensure that the desired outcomes for the patient are agreed on admission with the patient, families, provider and local care team.
Recommendation 21.	Commissioners should monitor the achievement of outcomes closely, intervening if outcomes are not being achieved in a timely manner.
Recommendation 25.	Commissioners should ensure the adoption of evidence-based prescribing by all providers.
Recommendation 33.	Commissioners should ensure that providers are taking considered positive risks and are not focusing exclusively on historical risk.
Recommendation 38.	Commissioners should ensure that all providers of restrictive intervention training comply with the 2019 Restraint Reduction Network Training Standards.
Recommendation 39.	Commissioners should ensure that providers have a restraint reduction plan in place for each patient.
Recommendation 41.	Commissioners should ensure that all blanket restrictions are proportionate, have a clear rationale for application and are subject to regular review.

Recommendation 46.	Commissioners should ensure that general healthcare staff have access to training on learning disabilities and autistic spectrum disorders.
Recommendation 47.	Commissioners should ensure that providers deliver best value.
Recommendation 48.	Commissioners should ensure that patients, families and carers have a voice in service design.
Recommendation 50.	Commissioners should ensure measures of patient satisfaction are obtained and used as indicators of responsive and quality services.
Recommendation 53.	Commissioners should ensure that patients with low Levels of Care that demonstrate that a less restrictive environment could meet their care needs are considered for transition.
Recommendation 55.	Commissioners should ensure that providers have a sufficient level of staffing to provide safe and progressive care.
Recommendation 57.	Commissioners should ensure that any outcomes that require contribution by therapy staff are being addressed.
Recommendation 62.	Commissioners should recognise and address the negative effects and impact of institutionalisation.
Recommendation 63.	Commissioners should ensure that all transition plans are enacted.
Recommendation 64.	Commissioners should ensure that all patients have a plan in place identifying the outcomes to be achieved in order to transition to the next step on their care journey.
Recommendation 67.	Commissioners should have in place a mechanism to review transition plans across the services they commission to ensure barriers to progress are removed.
Recommendation 68.	Commissioners should consider optimal planning arrangements for new models of enhanced inpatient services at a local, regional and national level.
Recommendation 69.	Commissioners should consider investment in early intervention and admission prevention community services.

Welsh Government

Recommendation 23. Welsh Government should consider establishing a national campaign to support the reduction in the inappropriate use of psychotropic medication.

Recommendation 70. To support transition and improve community services the Welsh Government should support Regional Partnership Boards to develop a sustainable funding model, including social investment and social enterprise.

Contents

PART A: Background 19

1. Introduction 20
2. Methodology Overview 21
3. Types of Provider 23
3.1. High Secure Hospitals 23
3.2. Medium Secure Hospitals 23
3.3. Low Secure Hospitals 24
3.4. Controlled Egress Hospitals 24
3.5. Uncontrolled Egress Hospitals 24
3.6. Assessment & Treatment Units 24
3.7. Continuing Care Units 24
3.8. Residential Care Homes 24
3.9. Supported Accommodation 25
3.10. Community Teams 25
3.11. Primary Care 25
4. Policy Context 27
5. Overview 28
6. Commissioners 29
7. Providers of Care 30
8. Service Transformation 31

PART B: Care in Numbers 33

9. Patient Gender 34
10. Age 35
11. Diagnosis 37
11.1. Learning Disability 37
11.2. Mental Health 39
11.3. Autistic Spectrum Disorder 40
11.4. Dementia 41
12. Admission Pathway 42
13. Length of Stay 45
14. Legal Status 49
14.1. Sections of the Mental Health Act 50
14.2. Reviewing Deprivation of Liberty Safeguards 51
15. Care Coordinator 53
16. Care Plans & Hospital Support Plans 55
16.1. Care Plan 55
16.2. Hospital Support Plan 56
17. Outcomes 58
17.1. Outcome - Reducing Behaviours That Challenge 60
17.2. Outcome - Reducing Self Harm 61
17.3. Outcome - Reducing Dependency 62
17.4. Outcome - Promoting Self-resilience 63
17.5. Outcome - Minimising Medication 64
17.6. Outcome - Participation in Psychological Interventions 65
17.7. Outcome - Reducing Accidental Self Injury 66
17.8. Meeting Patient Outcomes 67
18. Medication 69
18.1. Antipsychotics 71
18.2. Antidepressants 75
18.3. Mood Stabilisers 78
18.4. Anxiolytics, Sedatives & Hypnotics 80
18.5. Epilepsy Medication 84
18.6. Reducing the use of Psychotropic Medication 84
19. Medication Side Effects Monitoring 87
20. Behaviours that Challenge 90
20.1. Verbal Aggression 94
20.2. Purposeful Damage to Property 96
20.3. Violent Behaviour, No Physical Harm 98
20.4. Violent Behaviour, Causing Harm 100
20.5. Deliberate Self-Harm 102
20.6. Absconded from Hospital 104
20.7. Failed to Return from Leave 106
20.8. Sexually Inappropriate Behaviours 108
20.9. Harm from others (Vulnerability) 110
20.10. Other Behaviour that Challenges 112
20.11. Impact on Staff 114
20.12. Reducing Behaviours Which Challenge 114
21. Restrictive Interventions 116
21.1. Hands-on guidance 119
21.2. Time Out 120
21.3. Restraint, Not Floor 122

21.4. Supine Restraint 123
21.5. Seclusion 125
21.6. Prone Restraint 126
22. Reducing Restrictive Interventions 129
23. Personal & Blanket Restrictions 133
24. Dedicated Staff Support 136
25. Community Access 139
26. Physical Health 141
26.1. Access to Primary Care 141
26.2. Access to Secondary Care 144
26.3. Access to Urgent Care 145
27. Costs of Care 147

PART C: Patients Voice 149
27.1. Patient Experience & Satisfaction 151
27.2. Patient Satisfaction 151
27.3. Patient Experience 153
27.4. Circumstances of Admission 153
27.5. Experience of Care 154
27.6. Expectations 155
27.7. Raising Concerns 156

PART D: Ready to Care 157
28. Environment of Care 158
28.1. Privacy & Dignity 159
28.2. Ligature Minimised Environment 160
28.3. Empowerment 161
29. Levels of Care 163
29.1. Safety - Level of Care 163
29.2. Activities - Level of Care 166
29.3. Safety & Activities Level of Care 169
30. Staffing 170
30.1. Nurse Staffing 170
30.2. Therapists 171
30.3. Staff Training 174

PART E: The Patients Journey 177
31. Institutionalisation 178
32. Appropriate Environments of Care 180
32.1. Medium Secure 184
32.2. Low Secure 185
32.3. Controlled Egress 186
32.4. Assessment & Treatment 187
32.5. Uncontrolled Egress 188
32.6. Continuing Care 189
32.7. Transition 190

PART F: Appendices & References ...195
References 196
Appendix A: National Care Review Methodology 213
Appendix B: Triangulation of Measures 224
Acknowledgements 231

PART A
Background

'The Welsh Government is committed to improve the lives of its citizens and address inequalities where they exist.' [3]

1. Introduction

A learning disability is different from a specific learning difficulty such as dyslexia, or a mental health condition. Individuals with a learning disability have a significantly reduced ability to understand new or complex information and to learn new skills. These issues are apparent before adulthood is reached and have a lasting effect on development.[4]

Some individuals with a learning disability live in their own homes or with their families and require little or no support[5], whilst others have difficulties with interpersonal skills and activities of daily living and require significant and long term support.[6]

The Welsh Government's Learning Disability Improving Lives Programme focuses on keeping individuals as independent as possible and out of long-term institutional care.[7]

Despite aspirations to care for all individuals with a learning disability in the community, for some a hospital admission is required, and when this happens patients have the right to receive safe, effective, compassionate, evidence-based and outcome-focused care. The tragedies of Whorlton Hall[8], Winterbourne View[9], Southern Health[10] and Cornwall[11] demonstrate the catastrophic consequences of poor hospital care, whether provided by the NHS or independent sector.

In February 2019, Professor Jean White, Chief Nursing Officer, Welsh Government and Nurse Director NHS Wales, requested that the Director of Nursing, Quality and Performance at the NHS Wales National Collaborative Commissioning Unit undertake a National Care Review.

This National Care Review was to be undertaken in 2019 and to include all patients cared for in hospitals provided by NHS Wales or commissioned by NHS Wales from NHS England or the independent sector.

The Chief Nursing Officer expected that the review would provide information and assurance on the state of care, quality of care, patient experience and appropriateness of the patient's current placement.

2. Methodology Overview

A complete account of the methodology used for each section of this National Care Review can be found in **Appendix A.**

In the 2013 public inquiry into the scandal at the Mid Staffordshire NHS Foundation Trust Robert, Francis QC stated,

'The possession of accurate, relevant, and useable information from which the safety and quality of services can be ascertained is the vital key to effective commissioning.' [12]

This National Care Review is based on the sourcing of one hundred and fifty-six pieces of information on the admission, status, care, treatment and outcomes for each patient in relation to their current hospital inpatient episode, a total of 26,364 pieces of information.

The information that forms the basis of this National Care Review was gathered by trained and experienced nurses and social workers of the NHS Wales National Collaborative Commissioning Unit.

This National Care Review methodology was adapted from the 'Individual Progress Reviews' developed and currently used by the NHS Wales National Collaborative Commissioning Unit. Information was gathered, during site visits to each unit, from the patient, therapy staff, nursing team, clinical notes and prescription charts. It was not possible to have a discussion with the patients' families and carers due to the patients being adults with variable capacity.

Health Board Executive Directors of Nursing were informed of this National Care Review in a letter from the Chief Nursing Officer dated 4 February 2019 (restated in **Appendix A**).

The site visits were undertaken between February and June 2019. The information was collated, analysed and verified between July and September 2019. This National Care Review was drafted between October and December 2019 and presented to the Welsh Government in draft form in January 2020 with planned publication in February 2020.

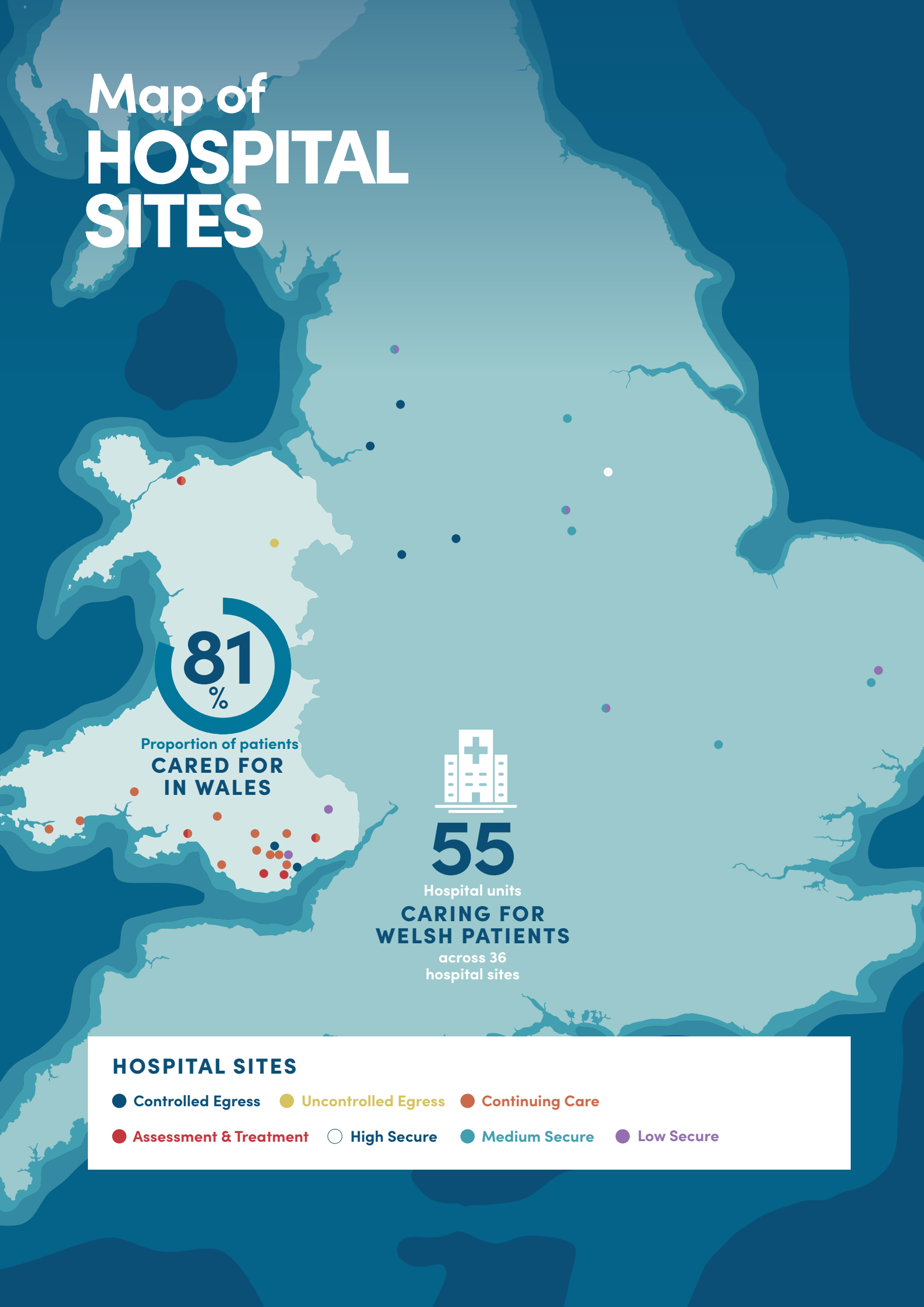
Patients, advocates and the All Wales People First Learning Disability Charity were consulted during this National Care Review.

26,364

PIECES OF INFORMATION

on patient care were gathered for this National Care Review

Map of HOSPITAL SITES



3. Types of Provider

Generally, within learning disability health services, the continuum of care ranges from community-based services to high secure units, with jurisdictions through these services differing in care delivery methodologies and service management hierarchies.

At the less restrictive end of learning disability services, many individuals live in their own home, with community-based support provided under the supervision of a care coordinator or case manager. Community-based care will be the default service option for most individuals with a learning disability.

For individuals requiring more direct support during a time of crisis, there are specific community services focused on providing urgent assessment and intervention.

Inpatient care is required when a more complex and detailed assessment is necessary or when the intervention cannot be carried out in the community.[13]

There are a range of inpatient units which offer specialised services for patients who have acute needs. These units offer open, locked or secure care dependent on the requirement to restrict egress and provide environmental, relational or procedural security.

Each of these services are detailed below.

3.1 High Secure Hospitals

High secure services are provided by three specialist hospitals in England that have physical security arrangements equivalent to a category B prison. Rampton Hospital in Nottinghamshire is designated as the hospital for patients with a primary diagnosis of learning disabilities. All individuals admitted to high secure services will be detained under the Mental Health Act and require the highest level of environmental and procedural security with access to a specialist forensic workforce. High secure services caring for patients from NHS Wales are commissioned by the Welsh Health Specialised Services Committee.

3.2 Medium Secure Hospitals

Medium secure services are specifically designed to meet the needs of patients who present a serious risk to themselves or others, combined with the potential to abscond. In many cases, patients in medium secure care will have committed an offence or been referred to hospital by the court services. Medium secure services are commissioned by the Welsh Health Specialised Services Committee, either directly from NHS Units in Wales, from NHS England or from the independent sector. The medium secure units directly managed by NHS Wales currently exclude patients with a primary diagnosis of learning disabilities.

3.3 Low Secure Hospitals

Low secure services are provided for those patients who have complex needs and cannot be safely cared for in non-secure units. These patients are usually detained under the Mental Health Act and present a level of risk to themselves and others that require specialist environmental security measures. Several health boards have these types of services for patients with mental health needs, but none for patients with a learning disability.

3.4 Controlled Egress Hospitals

Controlled egress services, previously termed 'locked rehabilitation', provide rehabilitative services to patients with complex needs and challenging behaviours. These units have locked or lockable doors to prevent unplanned egress. Many health boards have these types of services for patients with mental health needs, but none for patients with a learning disability.

3.5 Uncontrolled Egress Hospitals

Uncontrolled egress services, previously termed 'open rehabilitation', provide rehabilitative services to patients with longer-term needs. In general, these units only lock the entrances/exits at night for security purposes. Many health boards have these types of services for patients with mental health needs, but none for patients with a learning disability.

3.6 Assessment & Treatment Units

Assessment and treatment services are designed to be short-term placements for rapid assessment and acute treatment, with lockable doors. Some health boards have these types of services for patients with a learning disability.

3.7 Continuing Care Units

Continuing care services are units providing longer term care. Some of these facilities are hospital units and others have a culture and design akin to a residential care home. Some health boards have these types of services for patients with a learning disability.

3.8 Residential Care Homes

Residential care homes provide accommodation together with personal and/or nursing care. A resident in these homes will have a bedroom in a building normally shared with a number of other individuals. Usually, twenty-four-hour care will be provided on site and this may, or may not, include an element of care provided by registered nursing staff. These services are available, in various nature and degree, in all areas across Wales.

3.9 Supported Accommodation

Some individuals with a learning disability live in supported accommodation where they either live alone or share the home with a small number of other individuals with similar needs. There will usually be staff support, ranging from visiting to a twenty-four-hour presence. These services are available, in various nature and degree, in all areas across Wales.

3.10 Community Teams

When an individual with a learning disability requires specific assessments, interventions or ongoing support from health services beyond that provided by primary care, it will typically be provided by community teams of specialist learning disabilities nurses and social workers. These services are available, in various nature and degree, in all areas across Wales

3.11 Primary Care

When an individual with a learning disability requires assessment, advice or treatment from local health services they can visit a General Practitioner or nurse in local surgeries. They can also access advice and support from local social care services. These services are available, in various nature and degree, in all areas across Wales.

4. Policy Context

The 2014 Social Services and Well-being (Wales) Act provides the legal framework for improving the well-being of individuals who need care and support.[14]

In 2018, the Welsh Government launched the Learning Disabilities Improving Lives Programme.[15] This programme detailed a number of outcomes and recommendations to be delivered to improve the care and support provided to individuals with a learning disability. Two outcomes and recommendations in particular resulted in the commissioning of this National Care Review and are presented in Figure 1.

Figure 1:
Welsh Government Improving Live Programme – Pertinent Outcomes & Recommendations

Desired Outcome	Recommendation
To ensure that, when standards are set in services and outcomes monitored and evaluated, the needs of people with a learning disability are considered.	Standards, monitoring and evaluation – need to ensure appropriate standards and monitoring are in place.
Meeting specialist health care needs throughout the lifespan to ensure a good quality of life.	To ensure that people with complex needs have timely and easy access to LD specialist services through maintaining multi-disciplinary teams, reviewing health boards' bed-placed provision and developing appropriate care services.

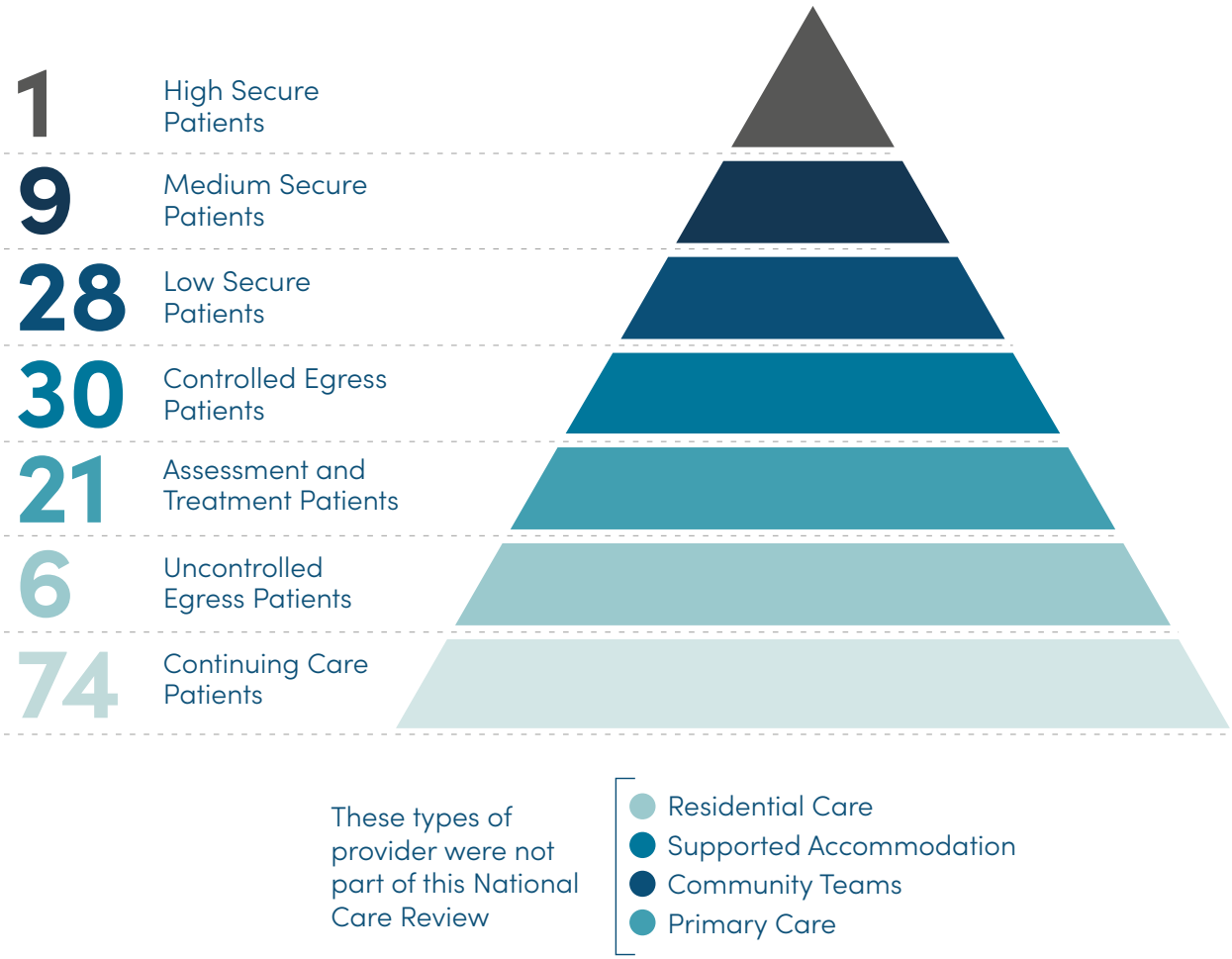
5. Overview

This National Care Review identified 256 patients with learning disabilities in units managed directly by, or commissioned by, NHS Wales. 169 patients (66%) were being cared for in units specialising in learning disabilities and 87 patients (34%) were being cared for in mental health units in Wales.[16]

This number compares to 2,270 patients with learning disabilities and/or autistic spectrum disorders in hospitals managed directly by, or commissioned by, NHS England, in April 2019.[17]

Figure 2 presents the types of providers, in a continuum from high secure hospital to community services, and the number of Welsh patients within each type of provider at the time of this National Care Review.

Figure 2:
Types of Providers with Patient Numbers as of 23 May 2019



6. Commissioners

In Wales, Health Boards are responsible for the provision or direct commissioning of care for their patients, except for certain specialist services such as high secure and medium secure care, which is commissioned through an NHS organisation called the Welsh Health Specialised Services Committee.

The majority of care for patients with a learning disability which is provided by services not directly managed by NHS Wales is commissioned through a National Collaborative Framework operated by the National Collaborative Commissioning Unit.

Six of the seven Health Boards had patients receiving inpatient care at the time of this National Care Review, with Powys Teaching Health Board the exception. Figure 3 presents each Health Board and the number of patients receiving care by type of provider.

Figure 3:

Responsible Health Board with Patient Numbers as of 23 May 2019

	High Secure	Medium Secure	Low Secure	Controlled Egress	Assessment & Treatment	Uncontrolled Egress	Continuing Care	Total
ANEURIN BEVAN UNIVERSITY HEALTH BOARD								
Male	1	0	8	1	3	0	6	19
Female	0	0	1	3	1	0	0	5
BETSI CADWALADR UNIVERSITY HEALTH BOARD								
Male	0	6	3	7	4	5	11	36
Female	0	0	1	3	0	1	3	8
CARDIFF AND VALE UNIVERSITY HEALTH BOARD								
Male	0	0	2	3	0	0	7	12
Female	0	0	1	3	3	0	6	13
CWM TAF MORGANNWG UNIVERSITY HEALTH BOARD								
Male	0	1	2	4	2	0	4	13
Female	0	0	0	1	1	0	6	8
HYWEL DDA UNIVERSITY HEALTH BOARD								
Male	0	1	4	0	0	0	9	14
Female	0	1	0	1	0	0	6	8
SWANSEA BAY UNIVERSITY HEALTH BOARD								
Male	0	0	4	1	4	0	12	21
Female	0	0	2	3	3	0	4	12
Total	**1**	**9**	**28**	**30**	**21**	**6**	**74**	**169**

7. Providers of Care

This National Care Review found that Welsh patients were being cared for in the full spectrum of units from high secure to continuing care. The map on page 22 shows the distribution of these units.

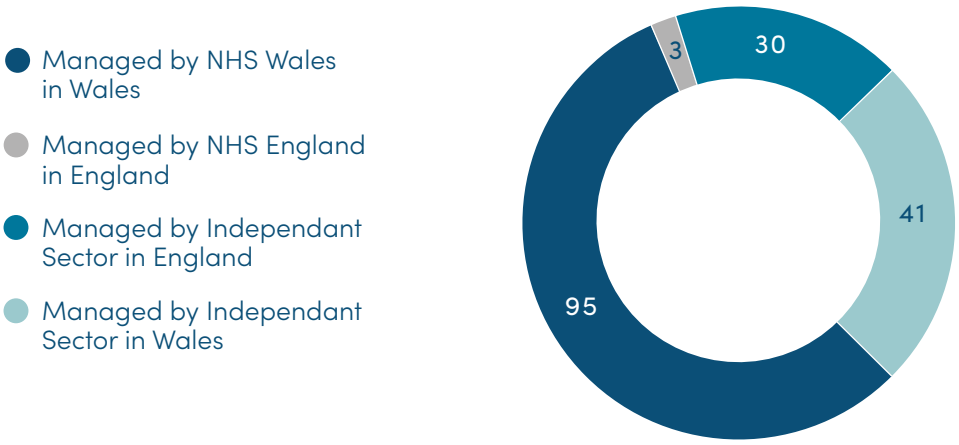
Reports from NHS England show that 60% of care was provided by the NHS, and 40% by the independent sector.[18]

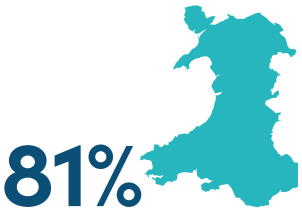
There were 169 patients identified who fell within the scope of this National Care Review:

- **95 patients (56%)** were cared for in services directly managed by Welsh Health Boards.
- **3 patients (2%)** were cared for in services managed by NHS England in England.
- **41 patients (24%)** were cared for in services commissioned by Welsh Health Boards from independent hospitals in Wales.
- **30 patients (18%)** were cared for in services commissioned by Welsh Health Boards from independent hospitals in England.

Figure 4 presents the distribution of Welsh patients by country and provider, and shows that the majority of patients (138, or 81%) were cared for in Wales.

Figure 4:
Number of Patients by Country & Provider





81%
Proportion of patients
CARED FOR IN WALES

8. Service Transformation

Learning disability services across the United Kingdom are currently experiencing extensive changes. NHS England is in the midst of a 'Transforming Care' programme which is ensuring that,

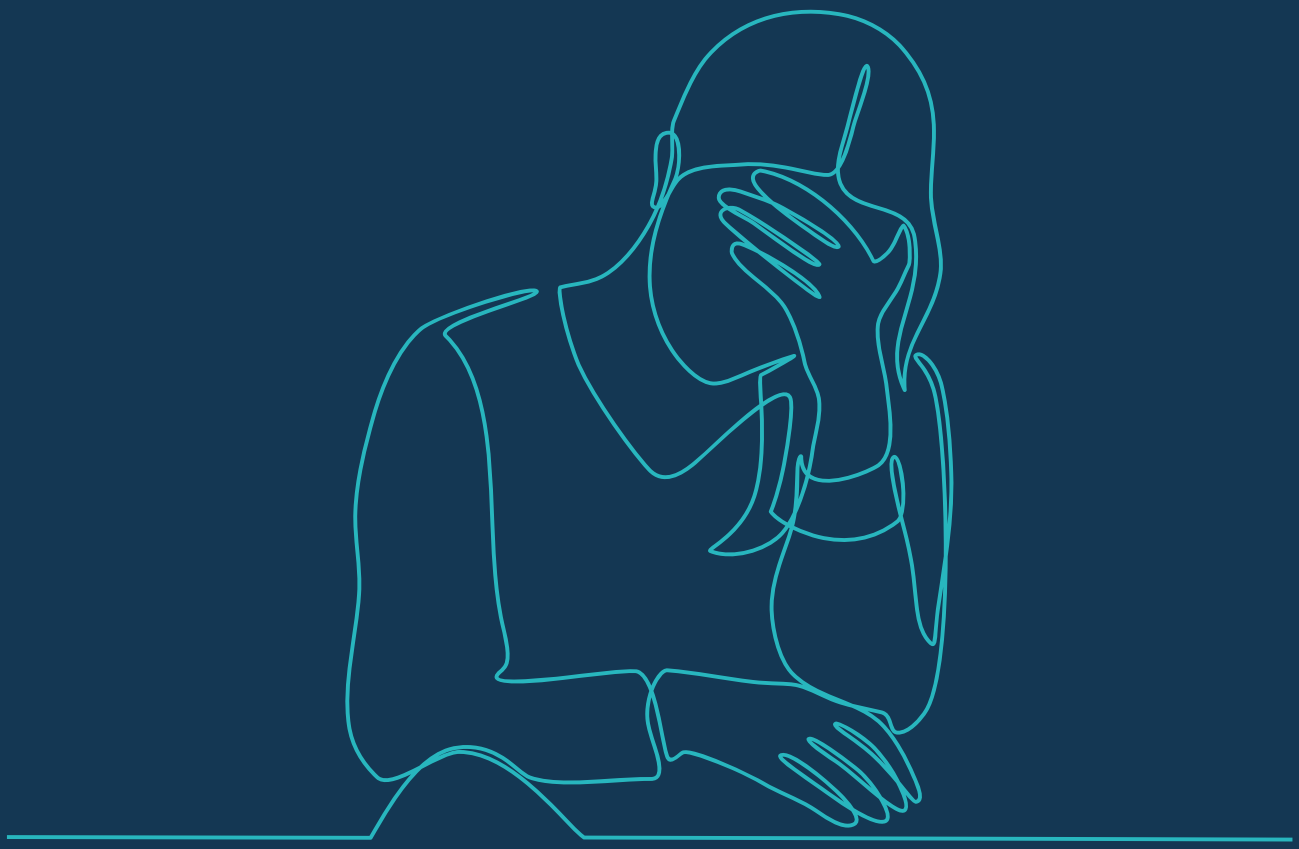
'People with a learning disability and/or autism in hospital who could be supported in the community are discharged into a community setting as soon as possible.' [19]

NHS England has also issued guidance around commissioning and service models in relation to patients with learning disabilities with behaviours which challenge. The guidance reinforces the need for effective strategic commissioning and for ensuring that persons with a learning disability are supported to live where and how they want.[20]

In NHS Wales, several Health Boards have been managing programmes to reduce hospital beds and to discharge long-stay patients, for several years. Some Health Boards, such as Aneurin Bevan and Hywel Dda University Health Boards, have recently reduced their hospital bed numbers.

PART B
Care in Numbers

'It is essential for Health Boards to have adequate and appropriate assurance processes in place to ensure that they have the right data available, and they are able to turn data into drivers for quality improvement and change.' [21]



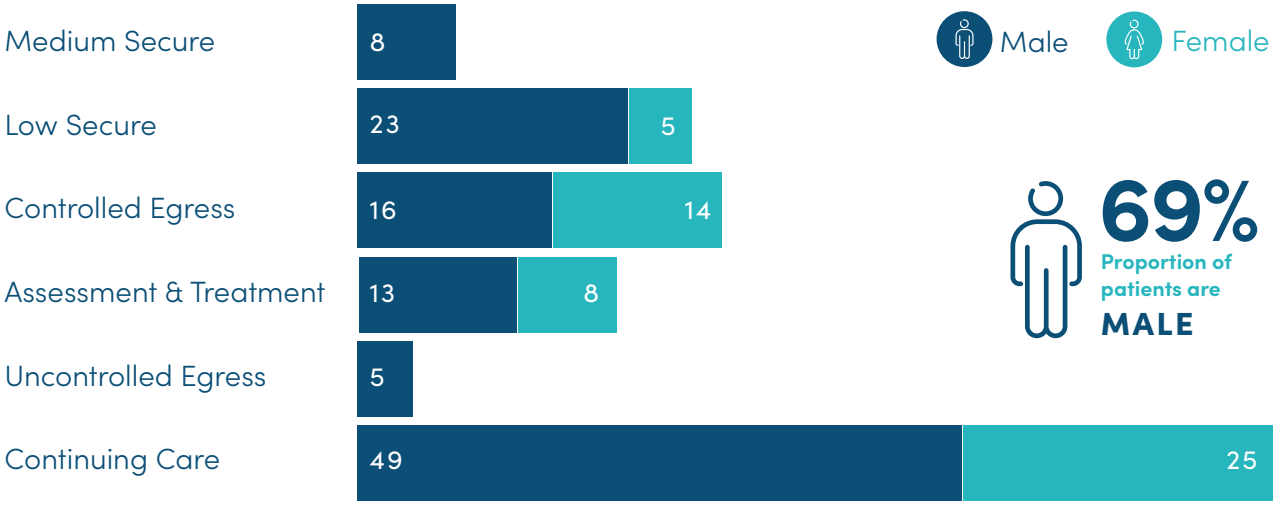
Note: Although there were 169 patients in hospital at the time of this Review, details of three patients have been excluded from Parts B-E. Please see notes section for explanation.

9. Patient Gender

Data from NHS England shows that 71% of patients with a learning disability and/or autism were male, and 29% were female.[22] Data from Scotland found 63% of patients were male and 37% female[23]. This National Care Review found a similar division for Welsh patients, with 114 patients (69%) being male and 52 (31%) female.

Figure 5 presents the number of patients by gender and type of provider and shows that medium secure units and uncontrolled egress units are exclusively male. In all types of provider there were more male patients than female patients.

Figure 5:
Male/Female Patients by Type of Provider & Gender



Studies have shown that there are differences between male and female patients with learning disabilities, especially in physical health needs and presentations.[24] Studies have also found that female patients with learning disabilities have different mental health needs than male patients, and such differences should be taken into account in the delivery of services.[25] Staff need to be aware of these differences in order to provide optimal care.

National Care Review Recommendations

1) **Providers should ensure that staff are aware of differences in presentation and need of male and female patients.**
2) **Commissioners should take account of the differences in the needs of male and female patients in the design and delivery of services.**

10. Age

This National Care Review found that the youngest patient was 18 years old and the oldest was 83 years old. It found that the average age of a patient was 43 years old and that female patients had a higher average age (45 years old) than male patients (42 years old).

Data from NHS England shows that the largest age banding of patients with a learning disability and/or autism was between 25 to 34 years old[26], whilst in Scotland the average age was between 21 to 34 years old.[27]

This National Care Review found that the highest number of patients were between 25 to 34 years old with 49 patients (30%) between these ages. Figure 6 presents the comparison between Scotland, English and Welsh patients by age banding, although the age boundaries do not align precisely.

Figure 6:
UK Comparison by Patients Age Band

	Wales %	England %	Scotland %
Under 18	Not collected as part of this National Care Review	11%	n/a
18 - 24 years old	9%	19%	7%*
25 - 34 years old	30%	29%	29%**
35 - 44 years old	17%	18%	19%
45 - 54 years old	18%	13%	21%
55 - 64 years old	19%	8%	13%
Over 65 years old	7%	2%	9%

Wales = 100%, Scotland 98% *[18-20] **[21-34]

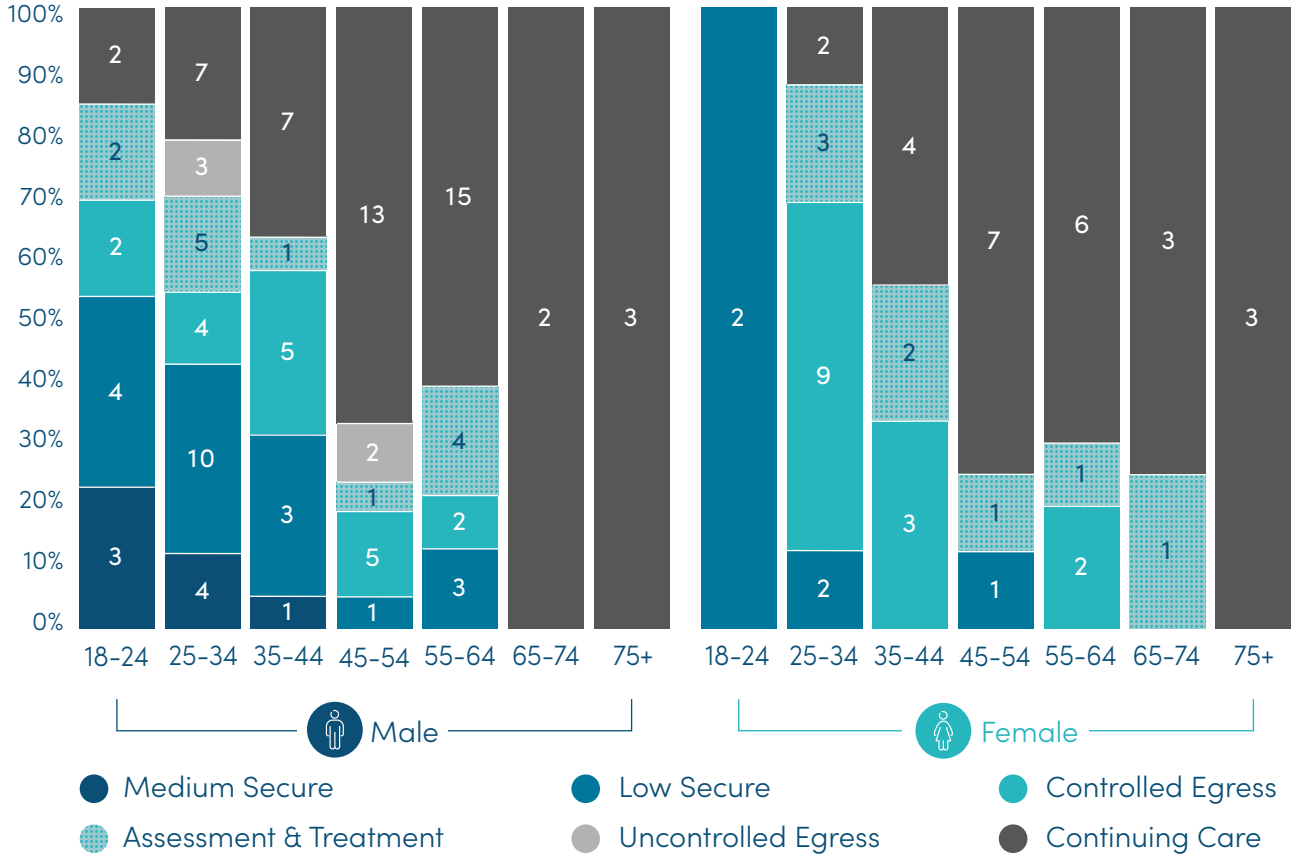
This National Care Review found that the type of providers caring for patients with the highest average age were continuing care units (52 years old), whilst medium secure units had patients with the lowest average age (27 years old).

Providers with the widest age ranges were continuing care units (between 24 and 83 years old), and the narrowest age ranges were medium secure units (between 22 and 37 years old).

Figure 7 presents the number of patients in each age banding, by gender and type of provider.

Figure 7:

Patients by Age Banding, Gender & Type of Provider



Although life expectancy is still much lower than the general population, individuals with learning disabilities are now living '*significantly longer*'. As they grow older, individuals with a learning disability have many of the same age-related health and social care needs as others, but they also face additional challenges associated with their learning disability.[28]

This National Care Review found that 61 patients (37%) were over 50 years old, with 12 (7%) being over 65 years old and 6 (4%) being over 75 years old.

Studies have recommended that staff are trained to understand the specific needs of older adults with a learning disability, including the need for proactive support that does not dismiss pain or other unexplained symptoms and knowledge of *'end-of-life'* care.[29] Environments of care may also require altering to meet the needs of older patients, such as the fitting of corridor handrails and adapting bathrooms.

National Care Review Recommendations

3) **Providers should ensure that staff are trained to recognise and meet the needs of older persons with a learning disability.**
4) **Commissioners should ensure that they have planned learning disability services to take account of an aging population profile.**

11. Diagnosis

Psychosis, bipolar disorder, dementia and autistic spectrum disorders are all more common in individuals with a learning disability than in those without.[30]

A high proportion of individuals receiving care in learning disability hospitals are diagnosed with additional mental health needs, autistic spectrum disorders or dementia*. This National Care Review found 117 patients (70%) had a secondary diagnosis.

This National Care Review found that 144 patients (87%) had a primary diagnosis of learning disabilities, 11 patients (7%) had a primary diagnosis of mental illness and 11 patients (7%) had a primary diagnosis of an autistic spectrum disorder.

70%

Proportion of patients with a

SECONDARY DIAGNOSIS

11.1 Learning Disability

Although it may be expected that all patients cared for in a learning disability hospital would have a primary diagnosis of a learning disability, it may be the case that a patient's needs, in respect to their mental health or autistic spectrum disorder, may be better met in these environments of care or by the staff skills available in such hospitals.

Data from NHS England shows that 99% of patients had a diagnosis of learning disabilities and/or autistic spectrum disorder.[31] This National Care Review found that 164 patients (99%) had a primary or secondary diagnosis of a learning disability or autistic spectrum disorder, with 144 patients (87%) having a primary diagnosis of learning disabilities.

* Note: There are many different diagnoses of mental disorders, dementia and types of autistic spectrum disorders. They have been grouped within these three categories for the purpose of this National Care Review. One patient with a primary diagnosis of acquired brain injury has been included under mental illness.

Figure 8 presents the secondary or tertiary diagnoses of patients with a primary diagnosis of learning disability.

Figure 8:

Secondary & Tertiary Diagnosis for Patients with a Primary Diagnosis of Learning Disability as a Proportion of all Patients

Primary Diagnosis & Secondary Diagnosis + Tertiary Diagnosis		Male (114)	Female (52)	Both Male & Female (166)
No secondary Diagnosis **Learning Disability**		**29 (25%)**	**17 (33%)**	**46 (28%)**
With Secondary Diagnosis **Mental Illness**		27 (24%)	28 (54%)	55 (33%)
+ Tertiary Diagnosis	ASD	8 (7%)	1 (2%)	9 (5%)
+ Tertiary Diagnosis	Dementia	2 (2%)	1 (2%)	3 (2%)
With Secondary Diagnosis **Autistic Spectrum Disorder**		28 (25%)		28 (17%)
+ Tertiary Diagnosis	Dementia	1 (1%)		1 (1%)
With Secondary Diagnosis **Dementia**		2 (2%)		2 (1%)
	Total	**97 (86%)**	**47 (90%)**	**144 (87%)**

11.2 Mental Health

Studies have suggested that, across the United Kingdom, 40% of adults with learning disabilities experience mental health problems at any point in time. These rates are much higher than for individuals without a learning disability.[32]

Factors relating to genetics, negative life events, less effective coping skills and negative interactions with others may all increase the risk of mental health issues in an individual with a learning disability. For individuals with learning disabilities, assessment and diagnosis of mental illness is not always effective, due to symptoms being misattributed to their learning disability, which challenges the effectiveness of current diagnostic tools.[33]

This National Care Review found that 80 patients (48%) had either a primary, secondary or tertiary diagnosis of mental illness. Figure 9 presents the secondary or tertiary diagnosis of patients, for the 11 patients with a primary diagnosis of mental illness.

Figure 9:

Secondary & Tertiary Diagnosis for Patients With a Primary Diagnosis of Mental Illness as a Proportion of all Patients

Primary Diagnosis & Secondary Diagnosis		Male	Female	Both Male & Female
With Secondary Diagnosis **Mental Illness**			**2 (4%)**	**2 (1%)**
With Secondary Diagnosis **Learning Disability**		2 (2%)	3 (6%)	5 (3%)
+ Tertiary Diagnosis	ASD	1 (1%)		1 (1%)
With Secondary Diagnosis **Autistic Spectrum Disorder**		3 (3%)		3 (2%)
	Total	**6 (5%)**	**5 (10%)**	**11 (7%)**

11.3 Autistic Spectrum Disorder

The term 'autism spectrum disorder' refers to a group of neurodevelopmental conditions defined by impairment in social interaction, communication, use of verbal and non-verbal language, restricted or repetitive pattern of behaviour, interests and activities.[34] Studies have shown that 1% of the general population have an autistic spectrum disorder[35] but 35% of individuals with a learning disability have an autistic spectrum disorder.[36]

This National Care Review found that 52 patients (31%) had either a primary, secondary or tertiary diagnosis of autistic spectrum disorder. All patients with a primary diagnosis of autistic spectrum disorder were male. Only one patient with a secondary diagnosis of an autistic spectrum disorder was female.

Figure 10 presents the secondary or tertiary diagnoses of the 11 patients with a primary diagnosis of an autistic spectrum disorder.

Figure 10:

Secondary & Tertiary Diagnosis for Patients With a Primary Diagnosis of an Autistic Spectrum Disorder as a Proportion of All Patients

Primary Diagnosis & Secondary Diagnosis + Tertiary Diagnosis		Male	Female	Both Male & Female
No secondary Diagnosis **Autistic Spectrum Disorder**		1 (1%)		1 (1%)
With Secondary Diagnosis **Learning Disability**		8 (7%)		8 (5%)
+ Tertiary Diagnosis	Mental Illness	1 (1%)		1 (1%)
With Secondary Diagnosis **Mental Illness**		1 (1%)		1 (1%)
	Total	**11 (10%)**	**0**	**11 (8%)**

11.4 Dementia

Dementia occurs at a much higher rate among individuals with a learning disability than those without.[37] Prevalence rates for dementia in the learning disabilities population have been estimated at 13% for those over 50 years old, and 22% for those over 65 years old.[38] Studies have found that individuals with dementia and learning disabilities were more likely to reside in '*health service accommodation*' than those with similar needs in the general population without learning disabilities.[39]

This National Care Review found that no patients had a primary diagnosis of dementia, but 6 patients (4%) had a secondary or tertiary diagnosis of dementia.

National Care Review Recommendations

5) **Commissioners should ensure that they have planned learning disability services to take account of patients with specific needs such as autistic spectrum disorders, dementia and mental illness.**
6) **Commissioners should ensure that staff are trained to recognise and meet the needs of patients with learning disability that are concurrent with other conditions such as an autistic spectrum disorder, dementia and mental illness.**

12. Admission Pathway

Developing good community services is important for supporting individuals with a learning disability to live how, and where, they want, and to avoid the need for hospital admission.[40]

Individuals are admitted into a learning disability hospital for many reasons, although it is notable that the presence of behaviour that challenges has often been shown to lead to community placement breakdown and hospital admission.[41]

This National Care Review found 153 patients (92%) with an admission source recorded. Figure 11 presents the number of patients with a specific admission source and found that 112 patients were admitted from another hospital and 41 patients were admitted from a community service.

Figure 11:
Number of Patients by Admission Source & Gender

	Male	Female
Home	6 (5%)	5 (10%)
Residential/Supported	18 (16%)	12 (23%)
NHS Hospital	50 (44%)	14 (27%)
Independent Hospital	33 (29%)	15 (29%)
Other/Unknown	7 (6%)	6 (12%)
Total	**114 (100%)**	**52 (100%)**

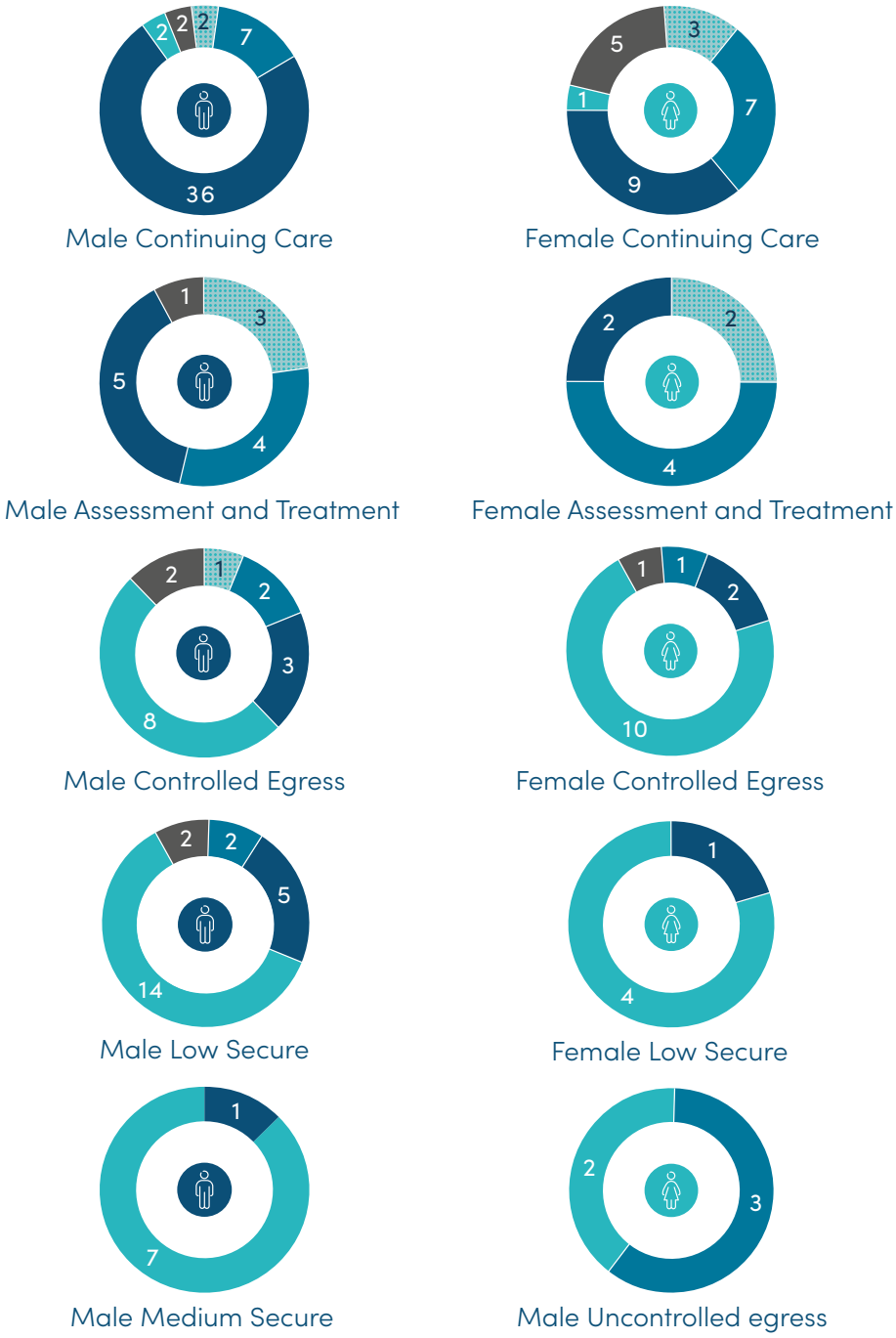
In terms of admissions into specific types of provider, the majority of both male and female patients in medium secure, low secure and controlled egress facilities were admitted from an independent sector hospital.

The majority of male patients admitted to assessment and treatment units were admitted from an NHS hospital, whilst female patients in these units were more likely to be admitted from a residential home or supported accommodation placement. Figure 12 presents the number of patients for each type of provider with a specific admission source, by gender.

67%
Proportion of patients admitted from
ANOTHER HOSPITAL

Figure 12:

Number of Patients by Admission Source for each Type of Provider



Studies have demonstrated that when individuals with a learning disability require hospital care they should have access to high-quality treatment in non-secure hospital services, with the clear goal of returning them to live in their home.[42]

National Care Review Recommendations

7) **Commissioners should identify those individuals most at risk of being admitted to hospital, so that the right support can be made available to prevent the need for admission.**
8) **Commissioners should have clear pathways in place to promote a 'community first' approach and to minimise transfer of patients from one hospital to another.**

13. Length of Stay

All commissioners should seek to minimise the patients' length of stay and any admissions should be supported by a clear rationale of planned assessment and treatment, with measurable outcomes.[43] Hospitals should not become anyone's *'de facto home'*.[44]

A review into learning disability hospitals managed by NHS Wales, published in 2016, stated that patients should not be '*residing*' in a hospital.[45]

This National Care Review found that the average length of stay** for patients from NHS Wales was 5.2 years, similar to patients from NHS England (5.3 years).[46]

This National Care Review found that the average length of stay was longer for female patients (5.8 years) than male patients (4.9 years).

Figure 13 presents the average length of stay, by time bandings, for patients from NHS England or Wales. It shows that Wales had more patients (36%) admitted for a year or less than England (28%). Wales (38%) had the similar number of patients admitted for more than five years as England (37%).

Figure 13:
Current Inpatient Admission by Time Bandings

	England	Wales
Up to three months	10%	10%
Three months to six months	7%	7%
Six months to one year	11%	19%
One year to two years	14%	11%
Two years to five years	21%	15%
Five years to ten years	21%	19%
Ten years or more	16%	19%

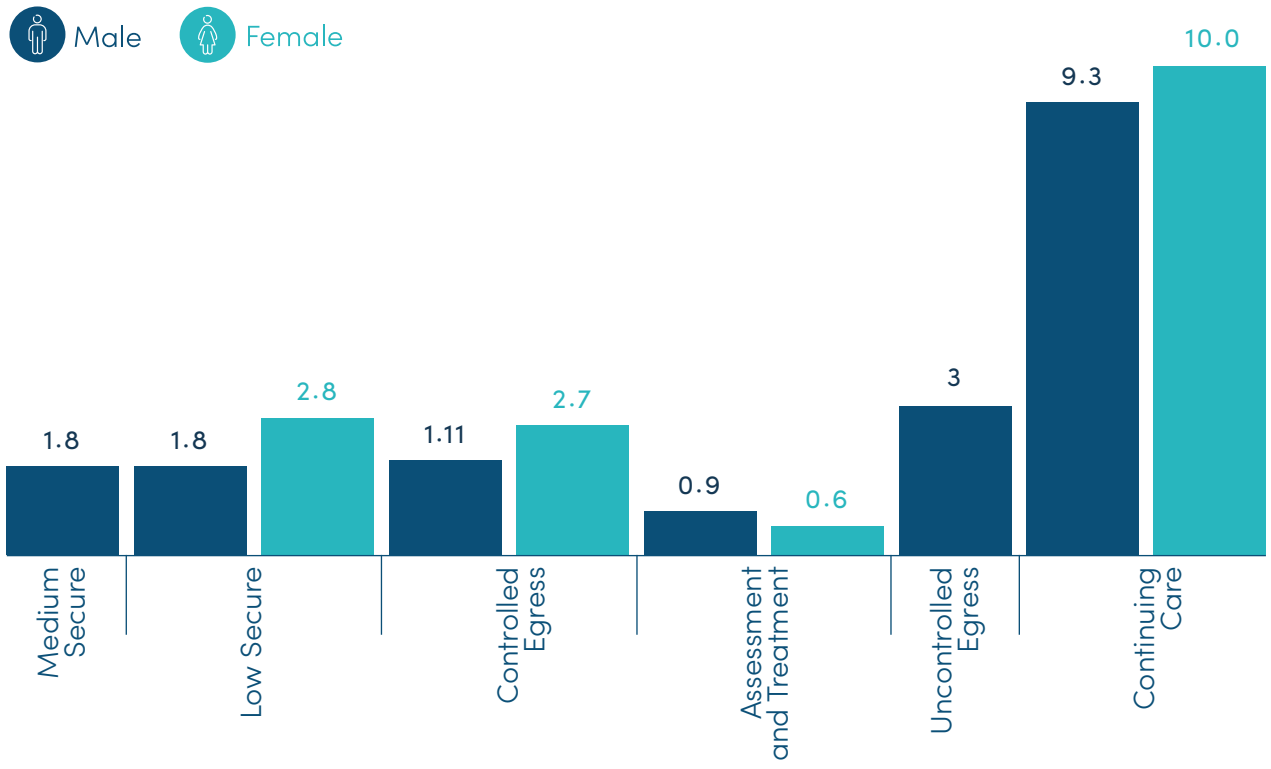
** Length of stay is usually reported as the period from the day of admission to the day of discharge. In this instance, it is the period from admission to the day of audit. Also note that the overall length of stay in hospital may be longer, as the patient could have been admitted from another hospital.

The average length of stay varied across different types of provider. This National Care Review found that the shortest lengths of stay were found in assessment and treatment units, whilst the longest were in continuing care units. The average lengths of stay, rounded down to the nearest month, were as follows:

- Male patients in **medium secure** units had an average length of stay of 668 days, or **1 year and 8 months.**
- Patients in **low secure** units had an average length of stay of 695 days, or **1 year and 9 months.**
- Patients in **controlled egress** units had an average length of stay of 794 days, or **2 years and 2 months.**
- Patients in **assessment and treatment** units had an average length of stay of 279 days, or **8 months.**
- Male patients in **uncontrolled egress** units had an average length of stay of 1102 days, or **3 years.**
- Patients in continuing care units had an average length of stay of 3475 days, or **9 years and 6 months.**

Figure 14 presents the length of stay for each patient in years, by type of provider and gender. It shows that female patients had longer average lengths of stay in all units except assessment and treatment units.

Figure 14:
Patients Average Length of Current Inpatient Admission in Years by Type Of Provider & Gender



The length of stay for each patient can vary depending on the needs of the patient, the therapy and care offered and the availability of suitable support on discharge.

This National Care Review found that the shortest length of stay was 2 days at the time of audit whilst the longest was 18023 days, or 49 years and 3 months. The accumulative length of stay for all patients was 859 years.

This National Care Review found 32 patients (19%) had a length of stay longer than 10 years and that these patients were all being cared for in continuing care units. Figure 15 presents the number of patients, by type of provider, gender and time bandings.

Figure 15:

Patients Length of Current Admission in Time Banding by Gender & Type of Provider

	Medium Secure		Low Secure		Controlled Egress		Assessment & Treatment		Uncontrolled Egress		Continuing Care	
	♂	♀	♂	♀	♂	♀	♂	♀	♂	♀	♂	♀
Up to three months	3		3		1		4	3			2	1
Three to six months			1	1		2	4	2	1		1	
Six months to one year	1		9		8	5	2	1	1		3	1
One year to two years	1		3	1	3	1	1	2			4	2
Two years to five years	2		5	2	2	4	1		2		4	3
Five years to ten years	1		2	1	2	2	1		1		14	7
Ten years or more											21	11

♂ Male ♀ Female

Individuals with a learning disability should only be admitted to hospital if assessment and care planning demonstrates that their needs cannot be met safely in the community and that all possibilities for doing so have been considered and exhausted.[47]

National Care Review Recommendations

9) **Commissioners should ensure that no hospital bed is classed as an individual's home, and every endeavour should be made to see community care as the 'default option' for all patients.**
10) **Commissioners should target resources at transitioning those patients in assessment & treatment units with a length of stay over one year, and those in other providers with a length of stay over five years.**

14. Legal Status

In many cases, when patients are treated in hospital they have agreed to an admission. However, there are cases when an individual with a 'mental disorder' can be detained, also known as 'sectioned', under the Mental Health Act (1983) and treated without their consent if necessary.

For most purposes, except for admission for assessment, a learning disability by itself is not considered a 'mental disorder' unless it is associated with '*abnormally aggressive*' with '*seriously irresponsible conduct by the patient*'.[48]

The Mental Capacity Act 2005 is a law that protects vulnerable individuals over the age of 16. When an individual does not have the capacity to consent to being in hospital, they can be 'deprived of their liberty' in order to keep them in hospital if professionals believe this is in their best interest. In such cases, protections need to be in place to prevent organisational misuse of these powers, and these protections are called 'Deprivation of Liberty Safeguards'.

An individual cannot be subject to a Section of the Mental Health Act and Deprivation of Liberty Safeguards simultaneously.

This National Care Review found that 92% of patients (152) were either subject to detention under the Mental Health Act or subject to Deprivation of Liberty Safeguards. Data from NHS England shows that 90% of learning disability patients in hospital are subject to a Section of the Mental Health Act.[49]

This National Care Review found that 57% of patients (94) were subject to a Section of the Mental Health Act and 35% (58) were subject to Deprivation of Liberty Safeguards.

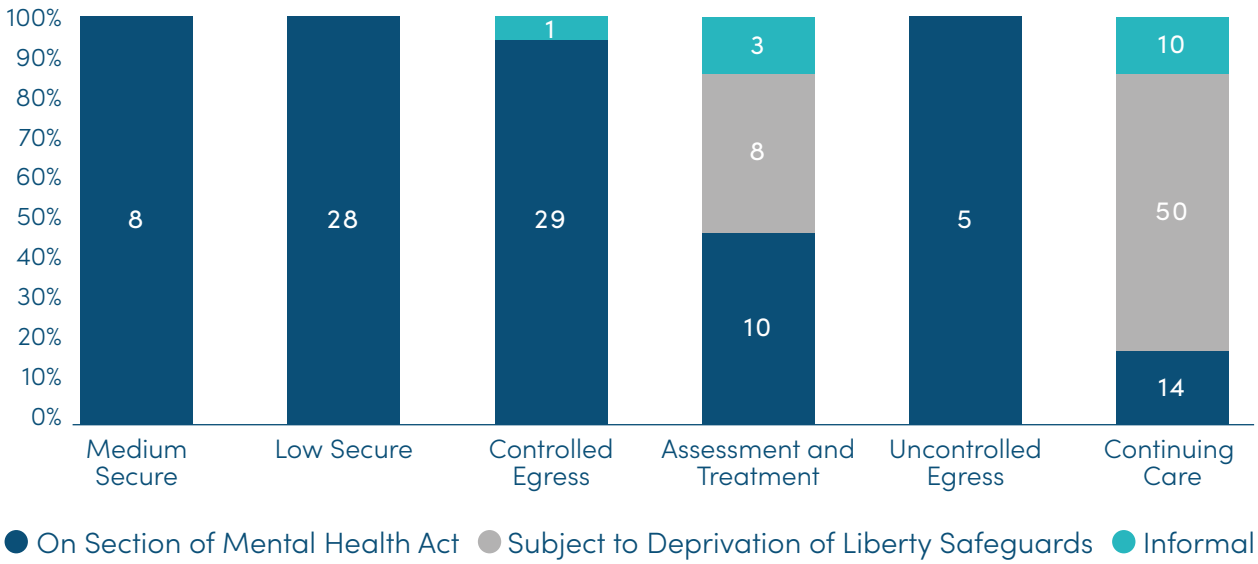
This National Care Review found that 14 patients (8%) were neither sectioned nor subject to Deprivation of Liberty Safeguards. It is possible that these individuals had capacity, although this could not be confirmed. No matter whether patients are content, compliant or voice no objections to being in hospital, capacity should be frequently reviewed.[50] Three of these 14 patients had been inpatients in assessment and treatment units for less than three months, whilst the remaining 11 had been inpatients in continuing care units for between four and seventeen years.

This National Care Review found that all patients in medium secure, low secure and uncontrolled egress hospitals were detained, and that the majority of patients in continuing care units were subject to Deprivation of Liberty Safeguards. Figure 16 presents the numbers of patients detained under the Mental Health Act, subject to Deprivation of Liberty Safeguards or neither (informal), by type of provider.

92%

Proportion detained under the MENTAL HEALTH ACT or subject to Deprivation of LIBERTY SAFEGUARDS

Figure 16:
Patients Legal Status by Type of Provider



14.1 Sections of the Mental Health Act

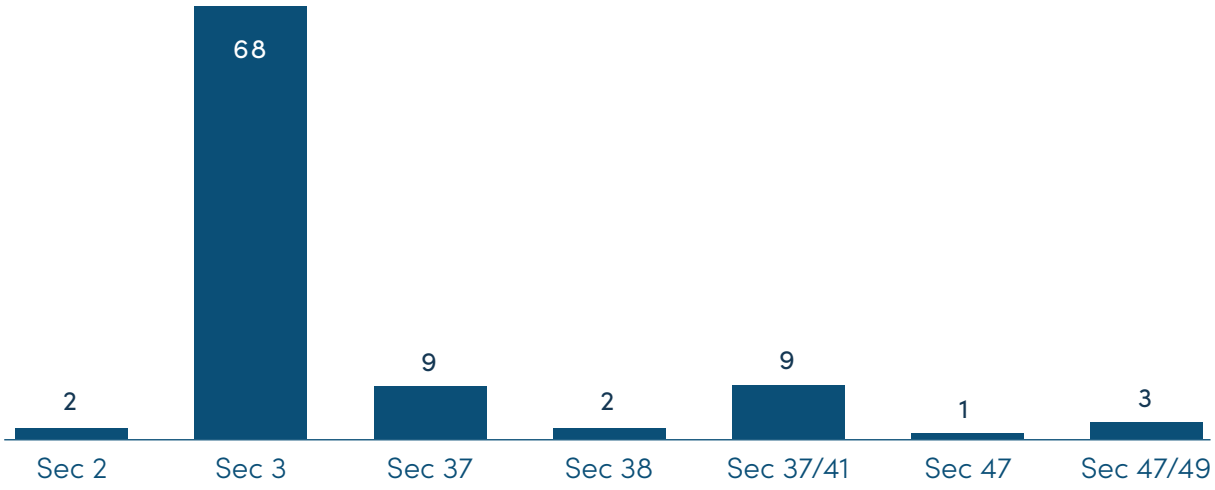
The Mental Health Act (1983), amended in 2007, is the main piece of legislation that covers the assessment, treatment and rights of individuals with a 'mental disorder'. The Mental Health Act (1983) has over one hundred sections.[51] Those relevant to the patients included in this National Care Review are as follows:

- **Section 2.** This is an assessment Section, although assessment can be followed by treatment. It lasts for a maximum of 28 days and cannot be extended.
- **Section 3.** This is a treatment Section. The initial period for which detention is authorised is six months, but it can be renewed for a further six months, then for further periods of 12 months.
- **Section 37.** This is a Section imposed by a Crown Court after an individual has been convicted of an imprisonable offence, other than murder. The stipulations are generally the same as an admission under Section 3, and is usually for treatment.
- **Section 37/41.** This Section has the basis of a Section 37, but unlike a Section 3 it does not require renewing as it continues indefinitely until discharged. The Ministry of Justice is responsible for granting leave and allowing discharge from hospital.
- **Section 38.** This Section is imposed by either a Crown Court or Magistrates Court. It is usually given after conviction but before sentence. It is an 'interim' order and it can last for an initial period of 12 weeks and then, if necessary, be extended up to 12 months. It is usually for assessment.
- **Section 47.** This is a Section for an individual who has received a sentence from a court and has been imprisoned. The Section transfers the individual from prison to a hospital for treatment.

- **Section 47/49.** This is a Section for an individual who has received a sentence from a court and has been imprisoned. The Section transfers the individual from prison to a hospital for treatment and means that the Ministry of Justice is responsible for granting leave and allowing discharge from hospital.

This National Care Review found that of the 94 patients detained under the Mental Health Act, the majority (68, or 72%) were detained under Section 3. Figure 17 presents the number of patients detained under different Sections of the Mental Health Act.

Figure 17:
Patients Detained by Section of the Mental Health Act



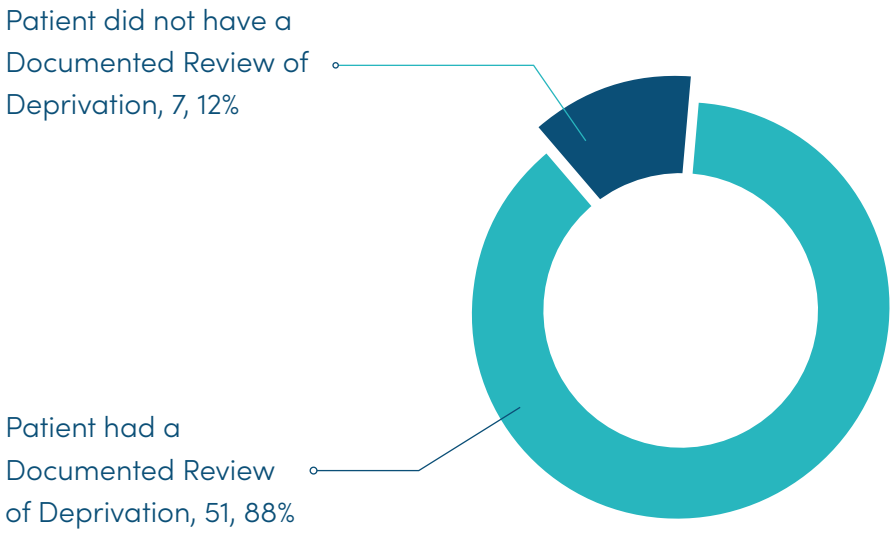
14.2 Reviewing Deprivation of Liberty Safeguards

It is an important principle of the Deprivation of Liberty Safeguards that an individual doing anything for, or on behalf of, an individual who lacks capacity should consider options that are less restrictive of their rights and freedoms while meeting their identified needs.[52]

Individuals with a learning disability may learn new skills which improve their capacity to make certain decisions, so capacity should be reviewed from time to time, especially whenever a care plan is being developed or reviewed.[53]

Figure 18 presents the proportion of the 58 patients that were subject to Deprivation of Liberty Safeguards who had a documented review of their deprivation within the 12 months prior to the National Care Review audit.

Figure 18:
Patients with a Documented Review of Deprivation of Liberty Safeguards within the Previous 12 Months



National Care Review Recommendations

11) Providers should ensure that all patients in hospital, who are not subject to detention under the Mental Health Act or to Deprivation of Liberty Safeguards have the capacity to consent to continue being an inpatient.
12) Providers should ensure that all patients subject to detention under the Mental Health Act or to Deprivation of Liberty Safeguards are aware of their rights.
13) Commissioners should ensure that all patients subject to detention under the Mental Health Act or to Deprivation of Liberty Safeguards are subject to regular review.

15. Care Coordinator

The care coordinator, sometimes called a case manager, manages the relationships between all members of the care team involved in caring for a patient. They do this by developing a care plan which details everyone's responsibilities, although they may also deliver certain components of the care plan themselves.

A care coordinator is responsible for working collaboratively with the patient and the patient's family to develop and review care plans. The care coordinator has a key role in ensuring the unit is suitable for the patient whilst in hospital, as well as planning the patient's accommodation needs on discharge to expedite transition.[54]

The arrangements for care coordination between community learning disability teams and inpatient settings is not always clear, and a recent report found it to be an area of '*profound confusion*'.[55]

Data from NHS England shows that 91% of persons with a learning disability in hospital had a care coordinator assigned.[56] This National Care Review found that 140 patients (84%) had a care coordinator assigned. All patients in medium secure, low secure, assessment and treatment and uncontrolled egress units had a care coordinator assigned. In controlled egress, 29 patients (97%) and in continuing care 49 patients (66%) had a care coordinator assigned.

The care coordinator can be a community learning disability nurse or social worker or both. Other health professionals such as psychologists or occupational therapists can also be a care coordinator if that arrangement best meets the patient's needs.

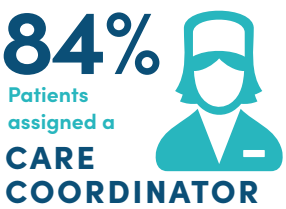
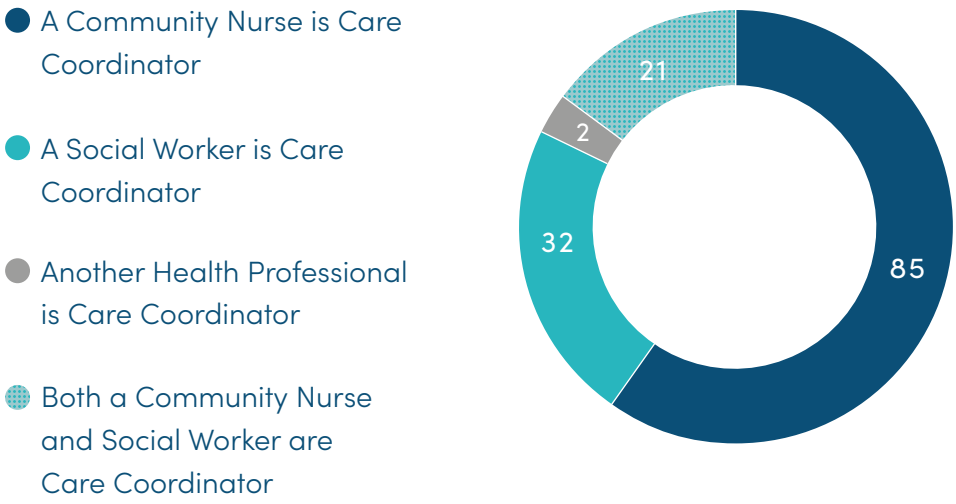


Figure 19 presents the number of patients assigned a care coordinator by care coordinator profession.

Figure 19:
Assigned Care Coordinator Profession



National Care Review Recommendations

14) **Commissioners should ensure that all patients in hospital are assigned a care coordinator.**
15) **Commissioners should ensure that all care coordinators understand their role in ensuring the patient is cared for in a safe and high quality environment and in planning and expediting the patient's transition.**

16. Care Plans & Hospital Support Plans

There are different names in use to describe the plan for the delivery of care to a patient, such as 'care and treatment plan', 'nursing plan', 'care plan', or 'support plan'.

For the purpose of this National Care Review, 'care plan' describes the longer term plan of care developed in the community or in hospital with the support of the community team, whilst 'hospital support plan' is the plan of care developed by the hospital team to address more immediate needs.

16.1 Care Plan

All individuals with a learning disability should have a care plan.[57] A care plan is a written record of needs, actions and responsibilities, which can be used and understood by individuals receiving care and their families. The process of care planning should enable individuals to take more control of their lives and ensure that their needs and aspirations have been taken into account.[58]

The National Care Review found that 130 patients (78%) had a care plan in place.

Care plans should be reviewed at least once a year.[59] Data from NHS England indicated that 4% of care plans did not have a documented date of the last review.[60] The National Care Review found that 3 (2%) of the 130 care plans did not have a documented date of the last review, although this may be a recording issue rather than an absence of review.

Figure 20 presents the time that had elapsed since the last formal care plan review. 'Formal review' means that an official record of the review has been made and shared with the patient, their family and commissioners.

Figure 20:
Time Since Last Formal Care Plan Review

	England	Wales
0-4 weeks	19%	15%
4-8 weeks	13%	9%
8-12 weeks	12%	10%
12-26 weeks	42%	30%
26-52 weeks	17%	14%
More than 52 weeks	2%	1%
No Review Date Documented	25%	2%
No Care Plan Document Available		22%

16.2 Hospital Support Plan

A hospital support plan is the document that facilitates person-centred, evidence-based and holistic care.[61] 'Person-centred' means that care begins with the individual and focuses on what the patient and the family think is important, as opposed to only what the healthcare professional considers necessary.[62]

Studies have shown that those individuals with communication difficulties, behaviour that challenges or severe learning disabilities are often excluded from the person-centred planning process.[63] Other studies suggest that patients in hospital were less likely to receive a person-centred approach to their care than those in other types of accommodation such as supported accommodation.[64]

The National Care Review found that all 166 patients (100%) had a hospital support plan in place and 90 plans (54%) evidenced that the patient had been involved in its development.

Figure 21:
Time Since Last Hospital Support Plan Review

	Number	%
0-4 weeks	100	60%
4-8 weeks	18	11%
8-12 weeks	11	7%
12-26 weeks	10	6%
26-52 weeks	9	5%
More than 52 weeks	5	3%
No Review Date	13	8%

Best practice recommends that hospital support plans are reviewed monthly[65] but three-monthly reviews would be acceptable for patients with longer lengths of stay. Figure 21 presents the time that had elapsed since the last hospital support plan review. It shows that 129 hospital support plans (78%) had been reviewed within 3 months.

It is Welsh Government policy to ensure that all patients have a support plan with agreed periodic reviews.[66]

100%
Patients with a hospital
SUPPORT PLAN

National Care Review Recommendations

16) Commissioners should ensure that care plans are reviewed regularly, within a maximum time period of six months.
17) Providers should ensure that hospital support plans are reviewed regularly, within a maximum time period of three months.
18) Commissioners should ensure that all care plans and hospital support plans are co-produced with the patient and with the involvement of the care coordinator and patients' families.
19) Providers should ensure that all care plans and hospital support plans are developed with specific objectives, measurable outcomes and clear timescales.

17. Outcomes

Outcomes are most commonly defined as the end result or impact of an intervention. However, given the enduring nature of some issues with the patient cohort within the scope of this National Care Review, outcomes have been defined as 'how things are for the patient now' or 'how the commissioners and patient would like them to be'.

In health services, outcomes are a measure of what happens to the health or well-being of the patient as a result of the treatment and care they receive.[67] Good services should focus on outcomes for the individual. Outcomes for patients with a learning disability should attend both to the challenge the individual presents and to supporting the individual to achieve a good quality of life.[68]

For individuals with a learning disability, admission to hospital should be supported by a clear rationale of planned assessment and treatment with measurable outcomes.[69] The care coordinator, unit staff and patient should be working together to develop a meaningful outcomes-based care plan.[70]

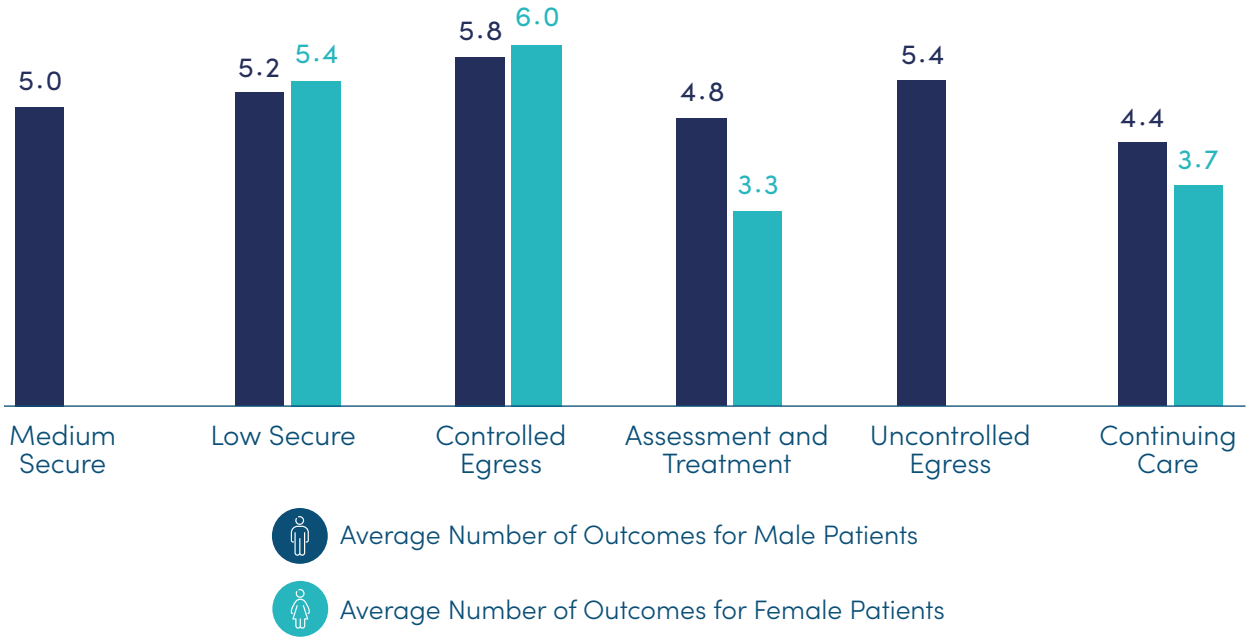
As they are based on the individual's needs, there are nearly limitless variations in possible outcomes. In order to reduce variation, enable comparison and support evaluation, the methodology supporting this National Care Review grouped outcomes into the following seven areas:

- Reducing Behaviours that Challenge.
- Reducing Self-harm.
- Reducing Dependency.
- Promoting Self-resilience.
- Minimising Medication.
- Participation in Psychological Interventions.
- Reducing Accidental Self-injury.

5
average number of
OUTCOMES
per patient out of a maximum of
7

This National Care Review found a total of 791 outcomes recorded for the 166 patients, of which 308 (39%) had been met. Patients had, on average, 5 out of a maximum 7 outcomes on admission; a higher number of outcomes can be considered a proxy for a greater degree of complexity. Figure 22 presents the average number of outcomes, by gender and type of provider.

Figure 22:
Number of Outcomes, Out of a Maximum of Seven, Per Patient by Gender & Type of Provider



This National Care Review looked at each patient's care plan, hospital support plan or admission documentation to evidence whether any of the outcomes were present on admission and whether any outcome had been met*** during the current inpatient admission.

Each of the seven outcomes will be discussed separately below. Reasons for not achieving one or more of the seven outcomes could include patient complexity, patient acuity, insufficient time, staff availability, staff skill mix, staff experience or the environment of care being unable to meet the patient's needs.

*** Note: The outcome may not have been fully achieved but may have been partially achieved to such a nature or degree as to warrant consideration of transition to a lower level of care.

17.1 Outcome – Reducing Behaviours That Challenge

Full Outcome. The individual is supported and enabled to reduce/minimise violence, aggression or behaviours that challenge others, through positive behavioural support/proactive risk management/strengths-based approach and with the minimal use of restrictive interventions.

This National Care Review found that this outcome was recorded for a total of 146 patients (88%) on admission, of whom 105 were male and 41 were female. Across the types of provider, this was the highest outcome for patients in medium secure, low secure and uncontrolled egress (100%) and the lowest outcome in uncontrolled egress unit (77%). The type of provider most often achieving this outcome was uncontrolled egress unit (60%), and least often was low secure unit (25%).

Figure 23 illustrates whether the outcome was recorded on admission and whether it had been achieved, by gender and type of provider.

Figure 23:
Patients with Reducing Behaviour That Challenge Outcome by Gender & Type of Provider

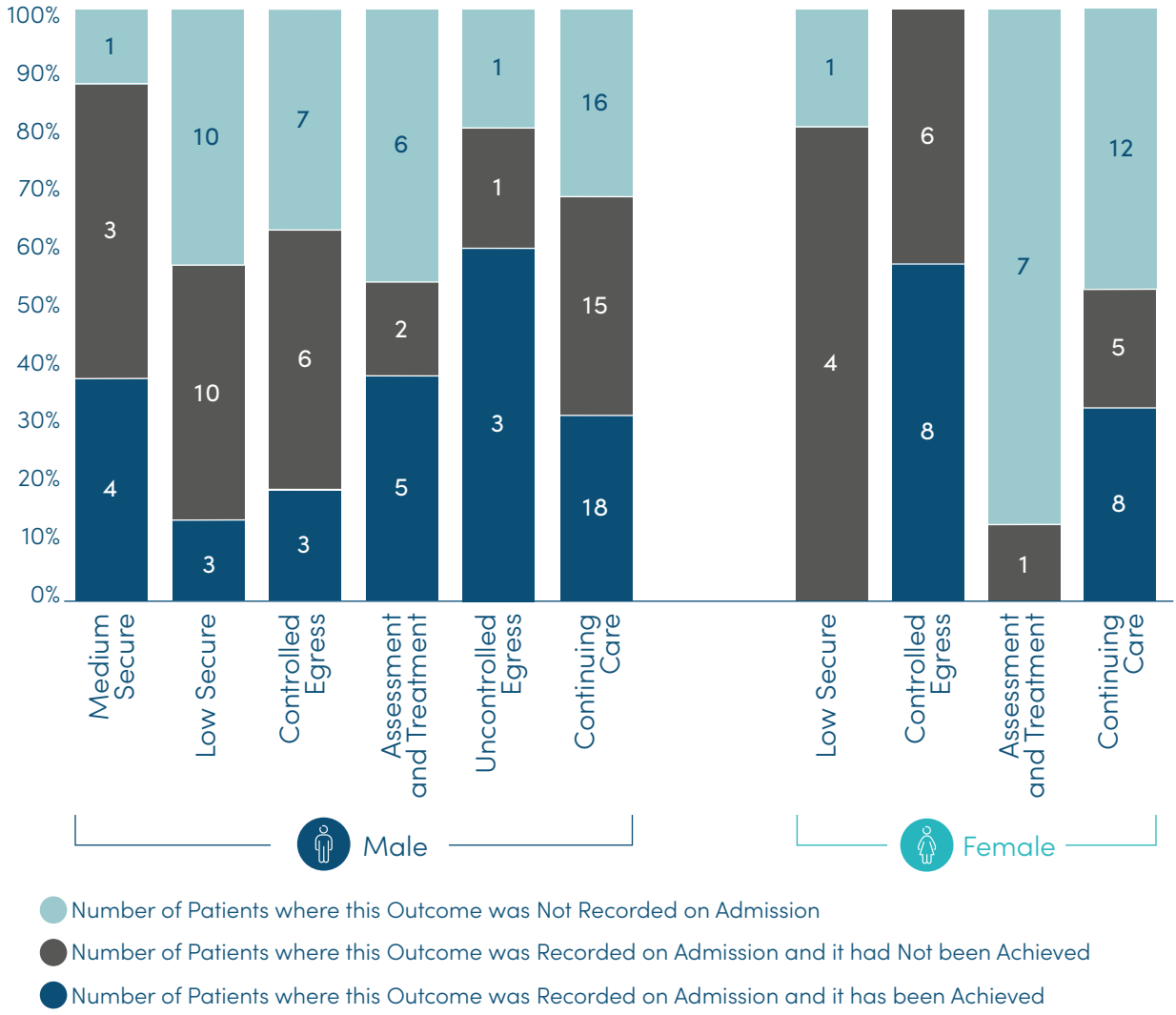
17.2 Outcome – Reducing Self-Harm

Full Outcome. The individual is supported and enabled to reduce/minimise occurrences of deliberate self-harm and/or self-harm ideology through positive behavioural support/proactive risk management/strengths-based approach and the minimal use of restrictive interventions.

This National Care Review found that this outcome was recorded for a total of 107 patients (64%) on admission, of whom 74 were male and 33 were female. Across types of provider, this was the highest outcome for patients in medium secure (87%) and the lowest outcome in assessment and treatment unit (38%). The type of provider most often achieving this outcome was uncontrolled egress (75%), and least often was low secure (18%).

Figure 24 illustrates whether the outcome was recorded on admission and whether it had been achieved, by gender and type of provider.

Figure 24:
Patients with Reducing Self Harm Outcome by Gender & Type of Provider



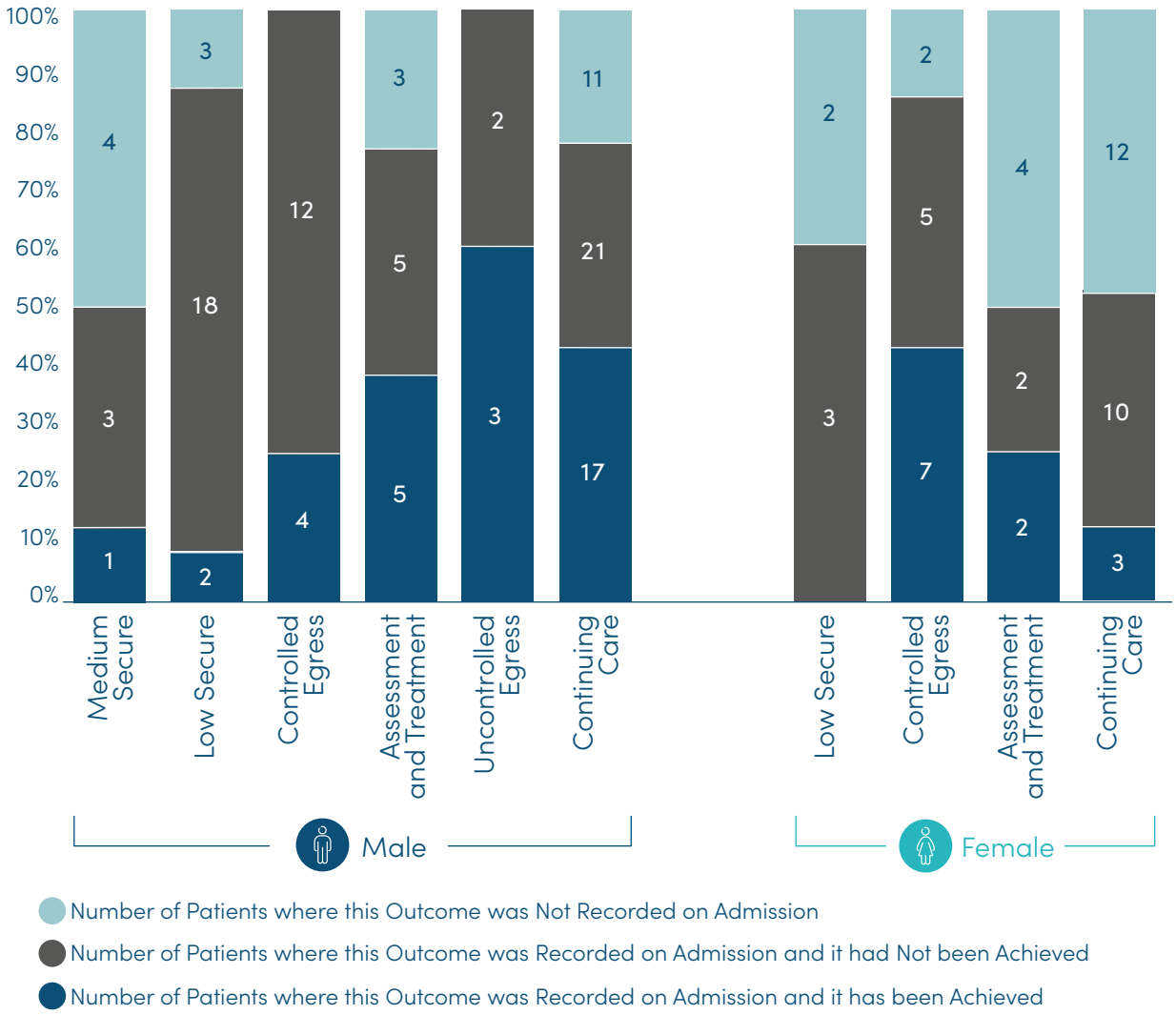
17.3 Outcome – Reducing Dependency

Full Outcome. The individual is supported and enabled to reduce dependency and independence is maintained and promoted through positive life skills and safe access to community services.

This National Care Review found that this outcome was recorded for a total of 125 patients (75%) on admission, of whom 93 were male and 32 were female. Across types of provider, this was the highest outcome for patients in uncontrolled egress (100%) and the lowest outcome in medium secure (50%). The type of provider most often achieving this outcome was uncontrolled egress (60%), and least often was low secure (8%).

Figure 25 illustrates whether the outcome was recorded on admission and whether it had been achieved, by gender and type of provider.

Figure 25:
Patients with Reducing Dependency Outcome by Gender & Type of Provider



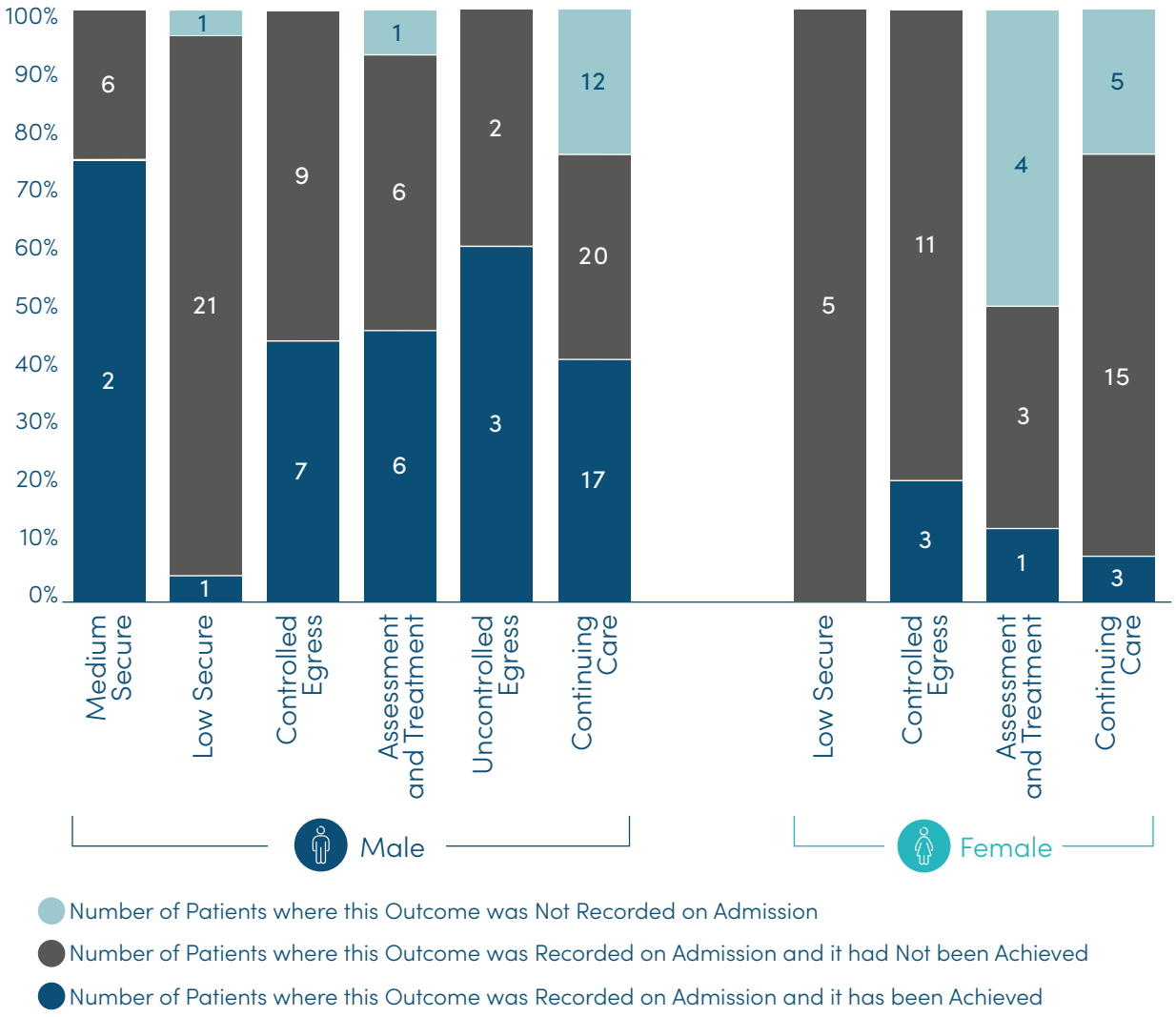
17.4 Outcome – Promoting Self-Resilience

Full Outcome. The individual's self-resilience is maintained and promoted through hope, positive regard, self-advocacy and a strength-based approach.

This National Care Review found that this outcome was recorded for a total of 141 patients (85%) on admission, of whom 100 were male and 41 were female. Across types of provider, this was the highest outcome for patients in medium secure, controlled egress and uncontrolled egress (100%) and the lowest outcome in continuing care (74%). The type of provider most often achieving this outcome was uncontrolled egress unit (60%), and least often was low secure (4%).

Figure 26 illustrates whether the outcome was recorded on admission and whether it had been achieved, by gender and type of provider.

Figure 26:
Patients with Promoting Self Resilience Outcome by Gender & Type of Provider



17.5 Outcome – Minimising Medication

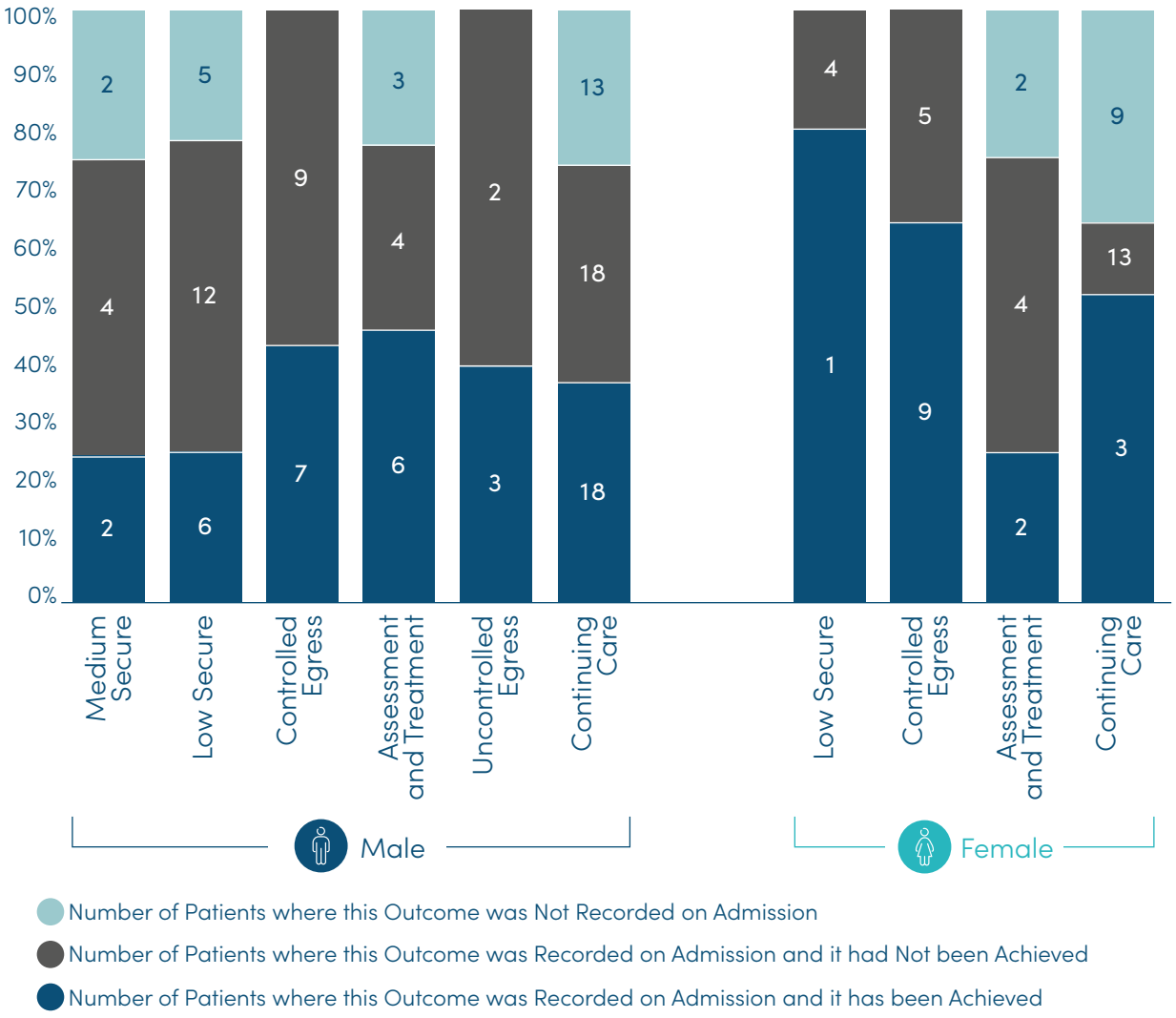
Full Outcome. The individual is supported and enabled to reduce/minimise symptoms of mental illness or distress through minimal use of pharmacology, whilst side-effects of prescribed medications are monitored, managed and minimised.

This National Care Review found that this outcome was recorded for a total of 132 patients (80%) on admission, of whom 91 were male and 41 were female. Across types of provider, this was the highest outcome for patients in controlled egress and uncontrolled egress (100%) and the lowest outcome in continuing care (70%). The type of provider most often achieving this outcome was uncontrolled egress and continuing care (60%), and least often was low secure (30%).

Figure 27 illustrates whether the outcome was recorded on admission and whether it had been achieved, by gender and type of provider.

Figure 27:

Patients with Minimising Medication Outcome by Gender & Type of Provider



17.6 Outcome – Participation in Psychological Interventions

Full Outcome. The individual is supported and enabled to achieve positive outcomes through specific individual or group, evidence based, psychological or psychosocial interventions.

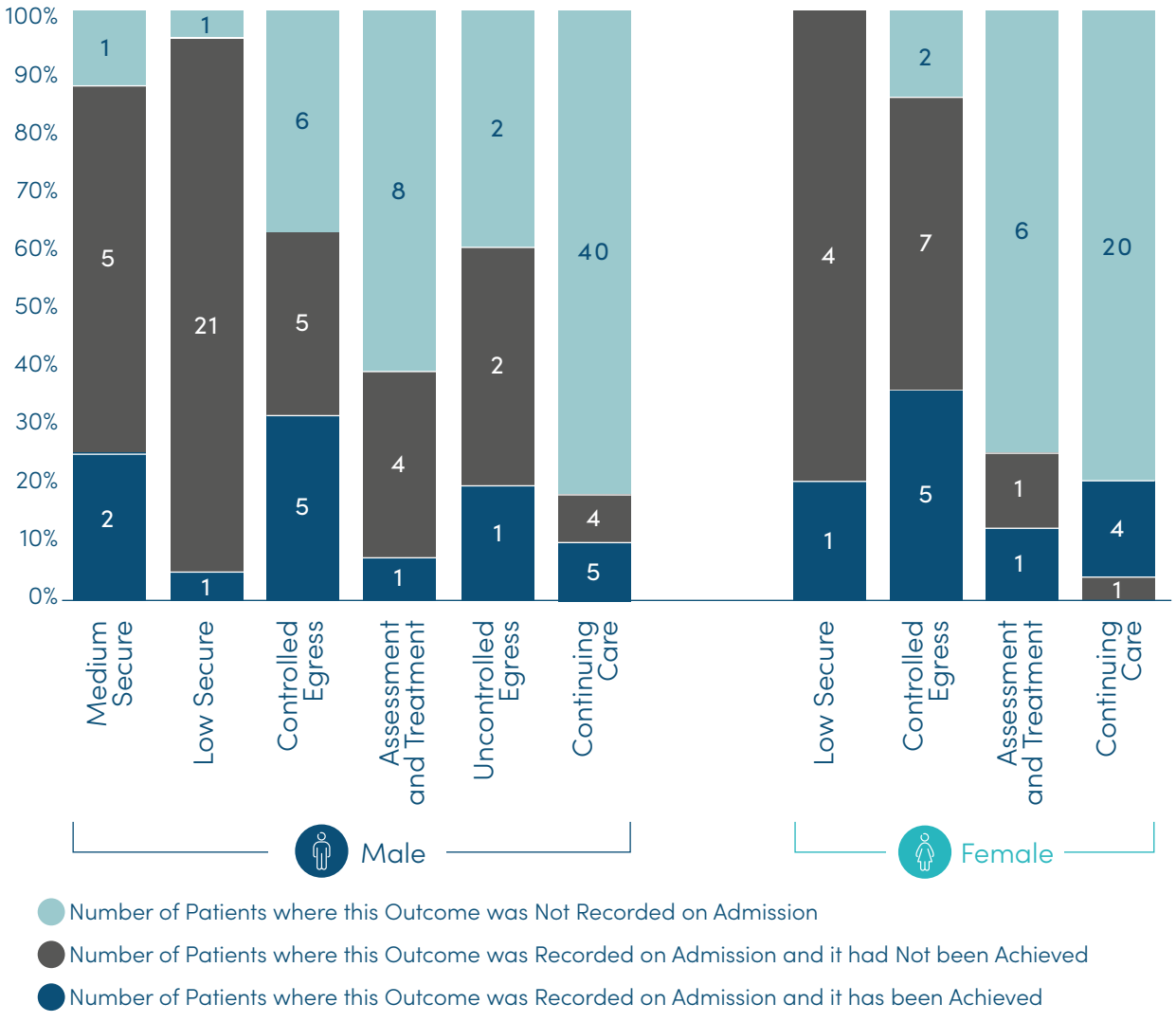
This National Care Review found that this outcome was recorded for a total of 80 patients (48%) on admission, of whom 56 were male and 24 were female. Across types of provider, this was the highest outcome for patients in low secure (96%) and the lowest outcome in continuing care (19%).

The type of provider most often achieving this outcome was controlled egress (45%), and least often was low secure (7%).

Figure 28 illustrates whether the outcome was recorded on admission and whether it had been achieved, by gender and type of provider.

Figure 28:

Patients with Participation in Psychological Interventions Outcome by Gender & Type of Provider



17.7 Outcome – Reducing Accidental Self Injury

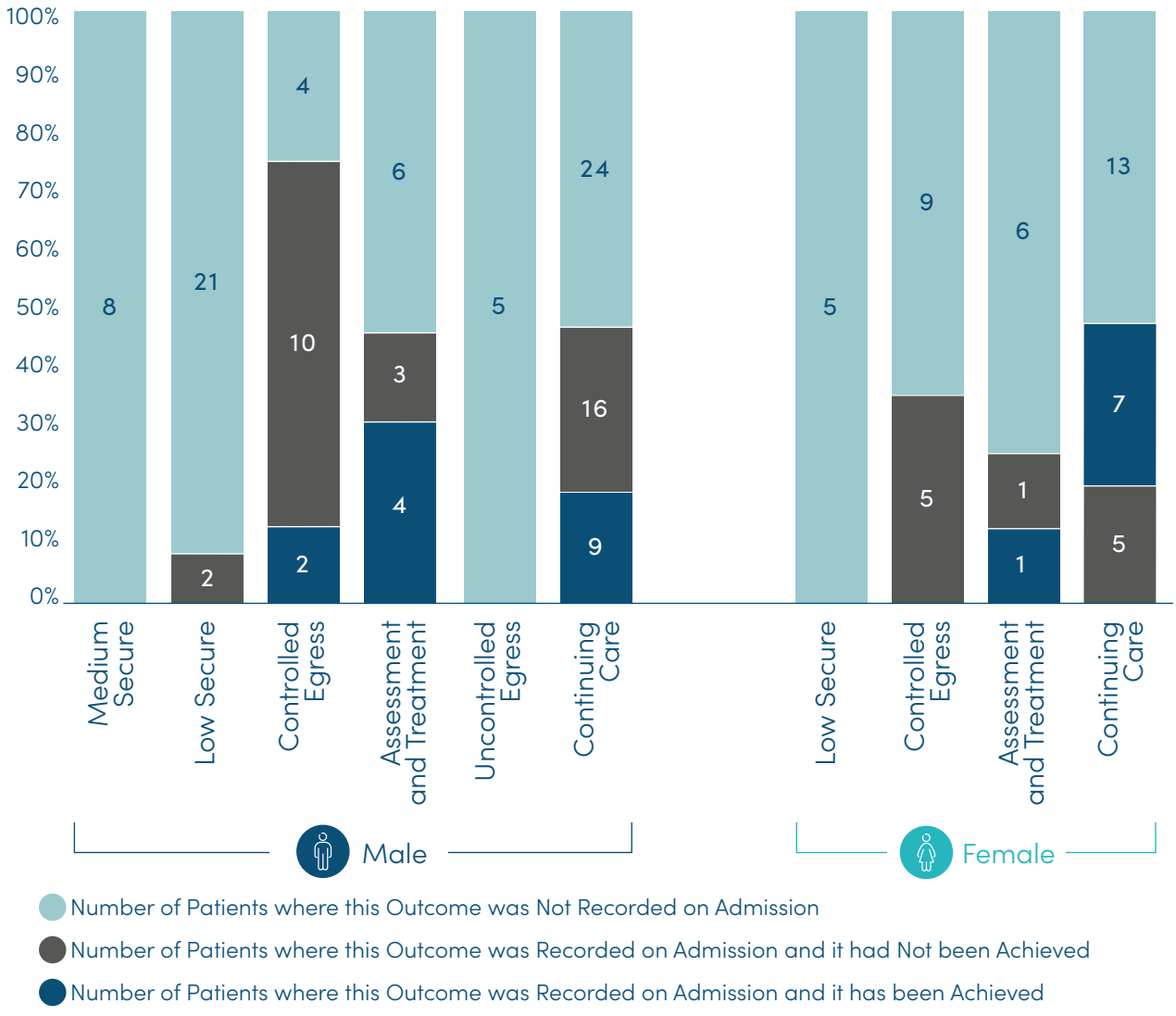
Full Outcome. The individual is cared for in a safe and secure environment to prevent unplanned egress and accidental self-injury whilst utilising minimal restrictive interventions and maximising of personal freedom.

This National Care Review found that this outcome was recorded for a total of 65 patients (39%) on admission, of whom 46 were male and 19 were female. Across types of provider, this was the highest outcome for patients in controlled egress (57%) and the lowest outcome in medium secure and uncontrolled egress (0%). The type of provider most often achieving this outcome was assessment & treatment (63%), and least often was low secure (0%).

Figure 29 illustrates whether the outcome was recorded on admission and whether it had been achieved, by gender and type of provider.

Figure 29:

Patients with Reducing Accidental Self Injury Outcome by Gender & Type of Provider



17.8 Meeting Patient Outcomes

The provision of care and support will be based on the outcomes that individuals want to achieve.[71] Good commissioning is person-centred and focuses on the outcomes that individuals say '*matter most to them*'.[72]

The National Care Review looked at the current admission and whether any, or all, of the patient outcomes that were recorded on admission had been met. Figure 30 illustrates the length of stay and the percentage of outcomes that had been met on average during the current admission. Overall, 39% of patients had their outcomes met during admission.

It takes time to meet outcomes, and there would be an expectation that the longer the inpatient stay, the greater the opportunity to meet the patient's outcomes. Figure 30 illustrates that 45% of patients whose inpatient stay had been over two years had their outcomes met.

Figure 30:

Patients with outcome recorded as being met by time bandings and type of Provider (absence of % denotes that there are no patients in that time band)

Length of stay Type of care	Outcomes met for patient with current length of stay of up to three months	Outcomes met for patient with current length of stay of three months up to six months	Outcomes met for patient with current length of stay of six months up to one year	Outcomes met for patient with current length of stay of one year up to two years	Outcomes met for patient with current length of stay of two years up to five years	Outcomes met for patient with current length of stay of five years up to ten years	Outcomes met for patient with current length of stay of ten years or more
Medium Secure	7%		83%	20%	80%	0%	
Low Secure	0%	0%	13%	22%	24%	14%	
Controlled Egress	0%	0%	24%	67%	71%	45%	
Assessment & Treatment	18%	58%	85%	60%	100%	80%	
Uncontrolled Egress		100%	0%		31%	100%	
Continuing Care	11%	100%	58%	65%	17%	51%	42%
Average number of outcomes met for time period	**10%**	**41%**	**31%**	**51%**	**43%**	**48%**	**42%**

Patient outcomes should be monitored constantly in order to ensure that they are being met in a timely manner. Meeting patient outcomes should be the primary focus of any inpatient admission.

National Care Review Recommendations

20) Commissioners should ensure that the desired outcomes for the patient are agreed on admission with the patient, families, provider and local care team.

21) Commissioners should monitor the achievement of outcomes closely, intervening if outcomes are not being achieved in a timely manner.

22) Providers should ensure that the patient's outcomes are discussed as part of the care plan and hospital support plan reviews.

18. Medication

The most prevalent form of treatment within learning disability inpatient services is pharmacological, not psychosocial. Medication can be an effective treatment option, but many patients with learning disabilities and behaviour which challenge will be subject to high rates of medication, the primary role of which is to act as a behavioural suppressant rather than a treatment.[73]

This National Care Review examined the prescription records of each patient to determine the types of medications being prescribed. Medications prescribed for physical health conditions were not considered as part of this National Care Review. Medication was categorised into five areas:

- Antipsychotics.
- Antidepressants.
- Mood stabilisers.
- Anxiolytics, sedatives and hypnotics.
- Epilepsy medication.

As Required Medication.

This is medication not prescribed regularly but administered by staff when required by the patient. It can sometimes be cited as PRN in medication charts (Pro Re Nata, a Latin phrase for 'in the circumstances').

Antipsychotics, antidepressants, mood stabilisers, anxiolytics, sedatives and hypnotics are categorised as 'psychotropic'. The phrase 'psychotropic' is a technical term for a group of medicines that alter chemical levels in the brain, which impact mood and behaviour or affect the central nervous system to relieve anxiety, aid sleep, or have a calming effect.

Studies have concluded that the rate of psychotropic medication prescription for individuals with a learning disability varies between 32% and 85%[74] [75], although some of these studies included individuals being cared for in the community and may not have included medication only administered 'as required' [see box]. One study found that 91% of patients with a learning disability who were detained in hospital under a Section of the Mental Health Act were prescribed one or more psychotropic medications.[76]

This National Care Review found that 150**** patients (91%) were prescribed one or more psychotropic medications. Figure 31 shows the psychotropic prescription rate across all patients and all care settings, by medication category.

91%

Patients prescribed one or more PSYCHOTROPIC MEDICATION

**** Note: One male low secure patient's medication record was unavailable at time of audit due to a general hospital admission, so the total patient numbers in this section total 165, not 166.

Figure 31:

Number of Patients Prescribed Psychotropic Medications

No medication	Prescribed a single type of psychotropic	Prescribed two types of psychotropic	Prescribed three types of psychotropic	Prescribed four types of psychotropic
No Medication **[15] [9%]**	Antipsychotics Only **[9] [5%]**	Antipsychotics + Antidepressants **[9] [5%]**	Antipsychotics + Antidepressants + Mood stabilisers **[4] [2%]**	Antipsychotics + Antidepressants + Mood Stabilisers + Anxiolytic/ Sedatives/ Hypnotics **[16] [10%]**
	Antidepressants Only **[5] [3%]**	Antipsychotics + Mood Stabilisers **[5] [3%]**	Antipsychotics + Antidepressants + Anxiolytic/ Sedatives/ Hypnotics **[36] [22%]**	
	Mood Stabilisers Only **[0] [0%]**	Antipsychotics + Anxiolytic/ Sedatives/ Hypnotics **[31] [19%]**	Antipsychotics + Mood Stabilisers + Anxiolytic/ Sedatives/ Hypnotics **[17] [10%]**	
	Anxiolytic/ Sedatives/ Hypnotics Only **[8] [5%]**	Antidepressants + Mood Stabilisers **[0] [0%]**	Antidepressants + Mood Stabilisers + Anxiolytic/ Sedatives/ Hypnotics **[0] [0%]**	
		Antidepressants + Anxiolytic/ Sedatives/ Hypnotics **[6] [4%]**		
		Mood stabilisers + Anxiolytic/ Sedatives/ Hypnotics **[4] [2%]**		

As with any medication, the use of psychotropic medications should always be monitored closely and prescribed only after other approaches, such as therapies and psychosocial education, have failed to produce the desired benefits.

As well as their main use in reducing the symptoms of mental illness, psychotropic medications can also be used as a 'chemical restraint'. 'Chemical restraint' refers to the use of medication which is administered for the purpose of subduing disturbed behaviour and not for the treatment of a formally identified physical or mental illness.[77] The use of psychotropic medications for the management of such behaviour should only be used as an intervention of last resort, after de-escalation techniques and positive support approaches have been attempted. The physical health of the individual should be monitored closely during and after the administration of psychotropic medication for safety purposes.[78]

This National Care Review found that of the 150 patients (91%) prescribed psychotropic medication, 132 (88%) had exhibited behaviour which challenges in the ninety days prior to this Review, and 147 (98%) had exhibited behaviour which challenges at any time during the admission.

A full multidisciplinary review should be conducted three months after prescribing any psychotropic medication and then at least every six months, and only those medicines that have shown a therapeutic benefit should be continued.[79] This National Care Review found that between 79% and 96% of prescriptions had been reviewed by a psychiatrist or GP during the twelve months previous to this review.

18.1 Antipsychotics

Antipsychotic medications are prescribed for individuals diagnosed with psychosis or affective disorders, such as bipolar disorder or severe depression. In those individuals with a learning disorder, the prevalence of psychotic disorders is estimated at 4% and that of affective disorders at 7%.[80] Antipsychotic medicines do not cure these conditions; they are used to relieve symptoms and improve the patient's '*quality of life*'.[81]

This National Care Review found that overall 127 patients (77%) were prescribed antipsychotics in some form. Figure 32 presents the form of antipsychotic prescriptions by the number and percentage of patients, by gender.

Figure 32:
Number of Patients Prescribed Antipsychotic Medications

	Number of Patients		% of Patients	
	Male	Female	Male	Female
Not prescribed antipsychotics in any form	22	16	19%	31%
Prescribed single antipsychotic	54	12	48%	23%
Prescribed single antipsychotic + antipsychotic 'as required'	15	10	13%	19%
Prescribed single antipsychotic + antipsychotic regular injection (depot)	0	1	0	2%
Prescribed more than one regular antipsychotic	5	6	4%	11%
Prescribed more than one regular antipsychotic + antipsychotic regular injection (depot)	2	0	2%	0
Prescribed more than one antipsychotic + antipsychotics 'as required'	6	2	5%	4%
Prescribed more than one antipsychotic + antipsychotics 'as required' + antipsychotic regular injection (depot)	0	1	0	2%
Prescribed antipsychotic by regular injection (depot) only	4	4	4%	8%
Prescribed antipsychotics 'as required' only	5	0	4%	0
Total	**113**	**52**	**100%**	**100%**

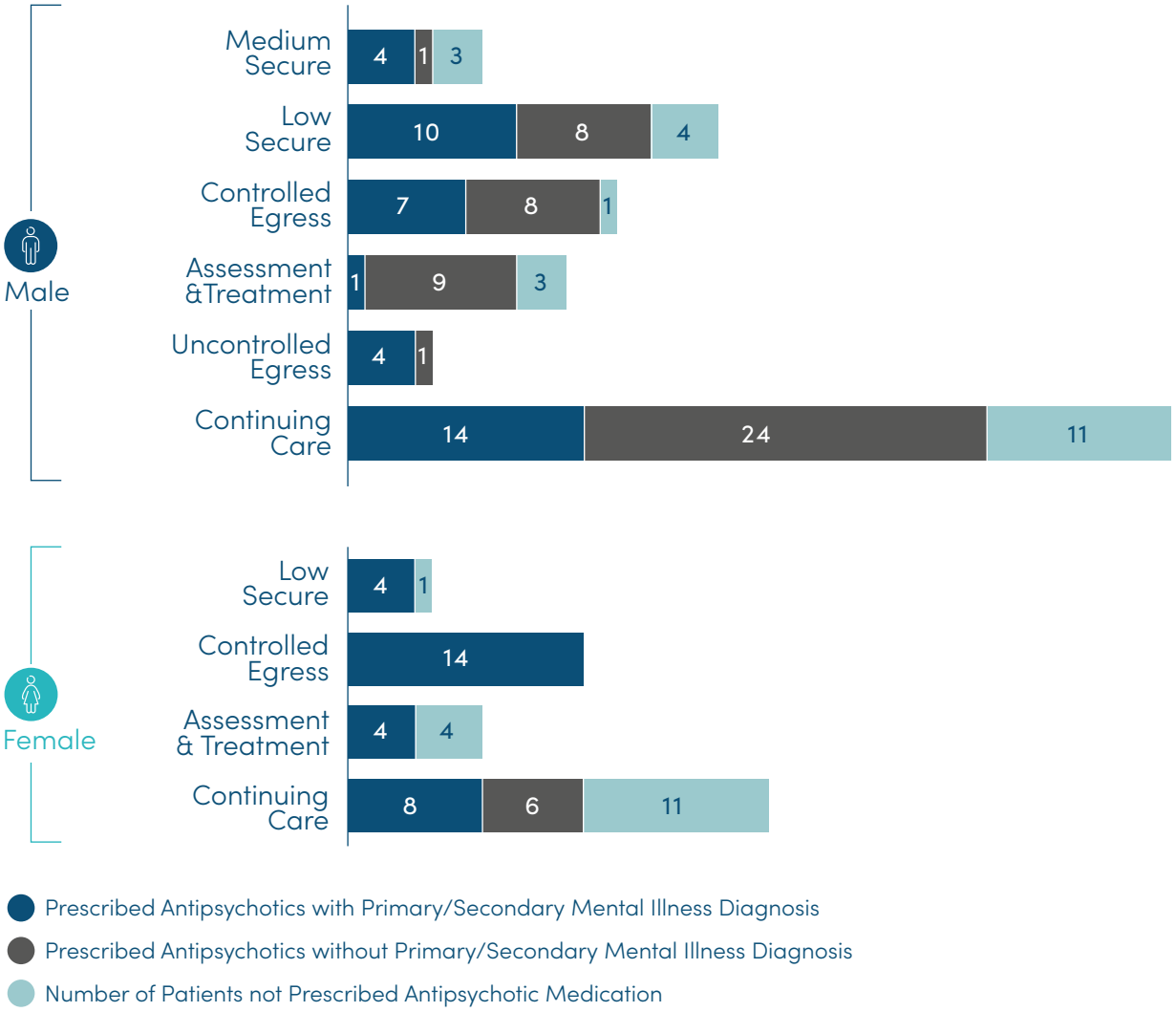
Although some studies have stated that there is a lack of evidence demonstrating the effectiveness of antipsychotics for individuals with a learning disability with no corresponding mental illness, prescribing of such medications is '*common practice*'. [82]

This National Care Review found that 57 (45%) of the 127 patients who were prescribed antipsychotics had no recorded primary or secondary diagnosis of mental illness. Studies have found that the proportion of individuals with learning disabilities prescribed antipsychotics '*far exceeded*' the proportion with recorded mental illness.[83]

Figure 33 presents the antipsychotic prescription rate where there was a corresponding primary or secondary diagnosis of mental illness, by type of provider and gender. It shows, when considering those patients prescribed antipsychotics, males were more likely to not have a mental illness diagnosis (51, or 31%) than females (6, or 12%).

Figure 33:

Number of Patients Prescribed Antipsychotic Medications With/Without Mental Illness

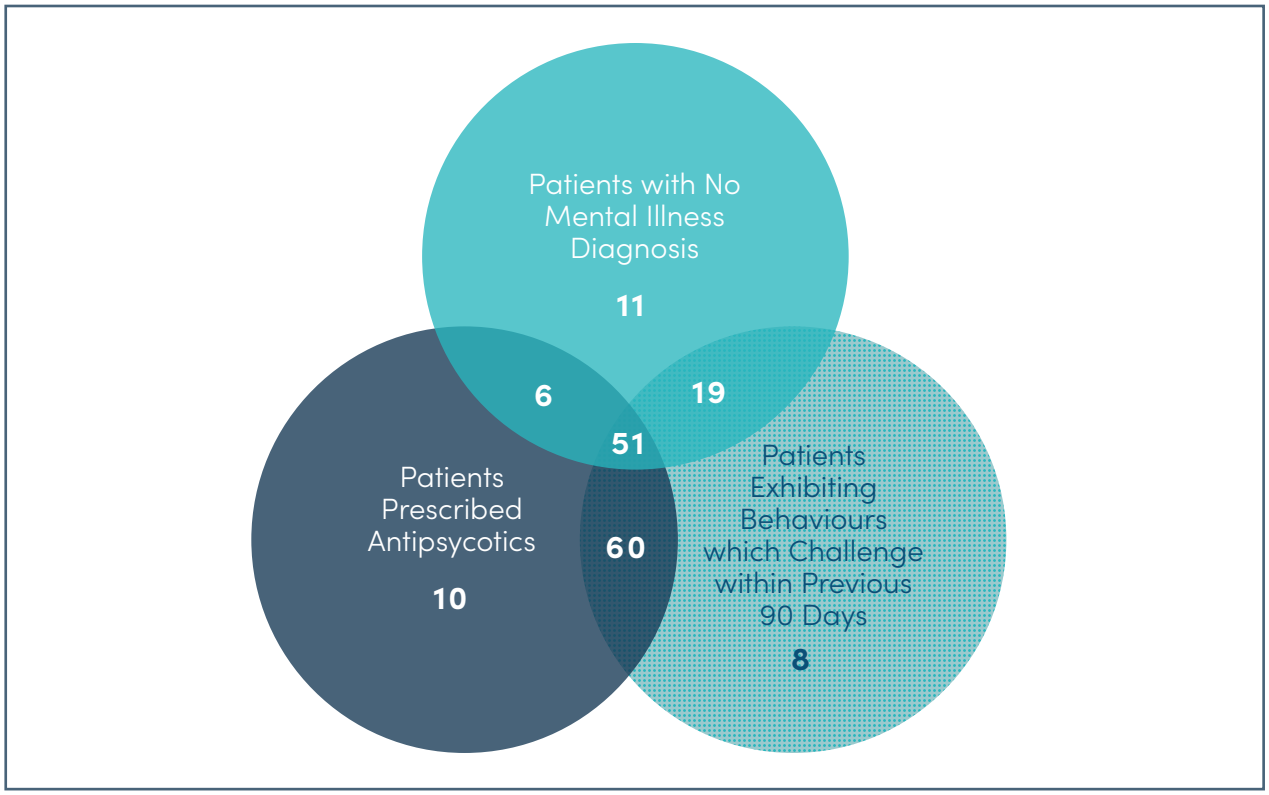


The most common reason for the prescribing of antipsychotics, where no mental illness is diagnosed, is the management of behaviours which challenge. Studies have shown that for 19%–58% patients antipsychotics are prescribed for the management of such behaviour.[84] [85]

Figure 34 presents the overlap between those patients prescribed antipsychotics, those patients with a mental illness and those exhibiting behaviours which challenge. The Figure shows that of the 127 patients prescribed antipsychotics, 111 (87%) had exhibited behaviours which challenged within the last ninety days and 127 (100%) had exhibited such behaviour since admission.

Figure 34:

Overlap Between Number of Patients Prescribed Antipsychotics/ Exhibiting Behaviours That Challenge/With Mental Illness



Antipsychotics can be utilised to manage behaviours which challenge if other interventions fail, after treatment of coexisting health problems and if the risk to the patient or to other persons is '*very severe*'. [86]

Appropriate management of behaviours which challenge is vital to prevent harm but studies have shown an *'over-reliance'* on antipsychotics for the management of such behaviour and that '*such use is off-licence and unsupported by empirical evidence'.* [87]

It has been noted that, for many patients with a learning disabilities, antipsychotics are being prescribed at '*higher doses*' than those recommended and, without being reviewed, continue to be prescribed for '*long periods*'.[88] Studies have also shown that it is difficult to withdraw these medications once commenced.[89] This National Care Review found that 109 patients (86%) had their prescription for antipsychotics reviewed by a psychiatrist or GP within the previous twelve months.

18.2 Antidepressants

Antidepressants are prescribed for individuals diagnosed with mood disorders such as depression and anxiety. The prevalence of mood disorders in those individuals with a learning disability is estimated at 7%, although reported prevalence rates for anxiety and depression amongst individuals with learning disabilities vary widely.[90] Some studies have reported prevalence rates to be at least similar to the general population[91], whilst others state that depression may be under-diagnosed for individuals with a learning disability, given that limited verbal skills may prevent some individuals reporting their mood.[92]

Studies show antidepressant prescriptions rates of 14% for individuals with a learning disability cared for in the community by primary care services.[93] Other studies of patients cared for in hospitals have shown antidepressant prescriptions rates as high as 37% and have suggested that antidepressants are '*commonly*' prescribed for indications other than mood and anxiety disorders.[94]

This National Care Review found that overall 76 patients (46%) were prescribed antidepressants in some form, with 46 male patients and 30 female patients being prescribed antidepressants. 74 patients (97%) were prescribed a single antidepressant and 2 (3%) were prescribed more than one antidepressant; no antidepressants were prescribed to be administered 'as required'.

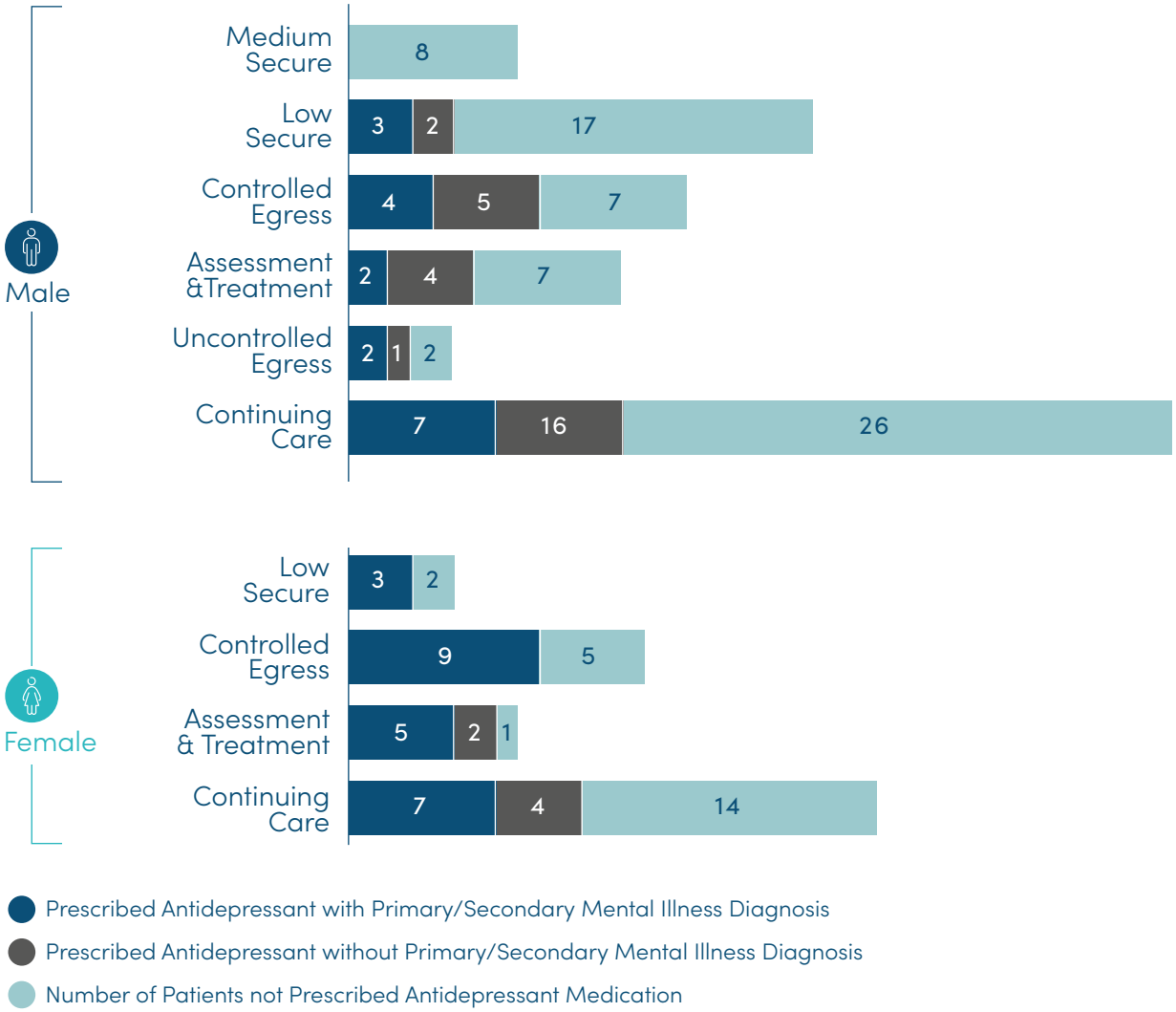
This National Care Review found that 34 (45%) of the 76 patients who were prescribed antidepressants had no recorded primary or secondary diagnosis of mental illness.

45%
Patients prescribed an antidepressant
WHERE THERE IS NO DIAGNOSIS OF MENTAL ILLNESS

Figure 35 presents the antidepressant prescription rate where there was a corresponding primary or secondary diagnosis of mental illness, by type of provider and gender. It shows, when considering those patients prescribed antidepressants, that males were more likely to not have a mental illness diagnosis (28, or 25%) than females (6, or 12%).

Figure 35:

Number of Patients Prescribed Antidepressant Medications With/Without Mental Illness

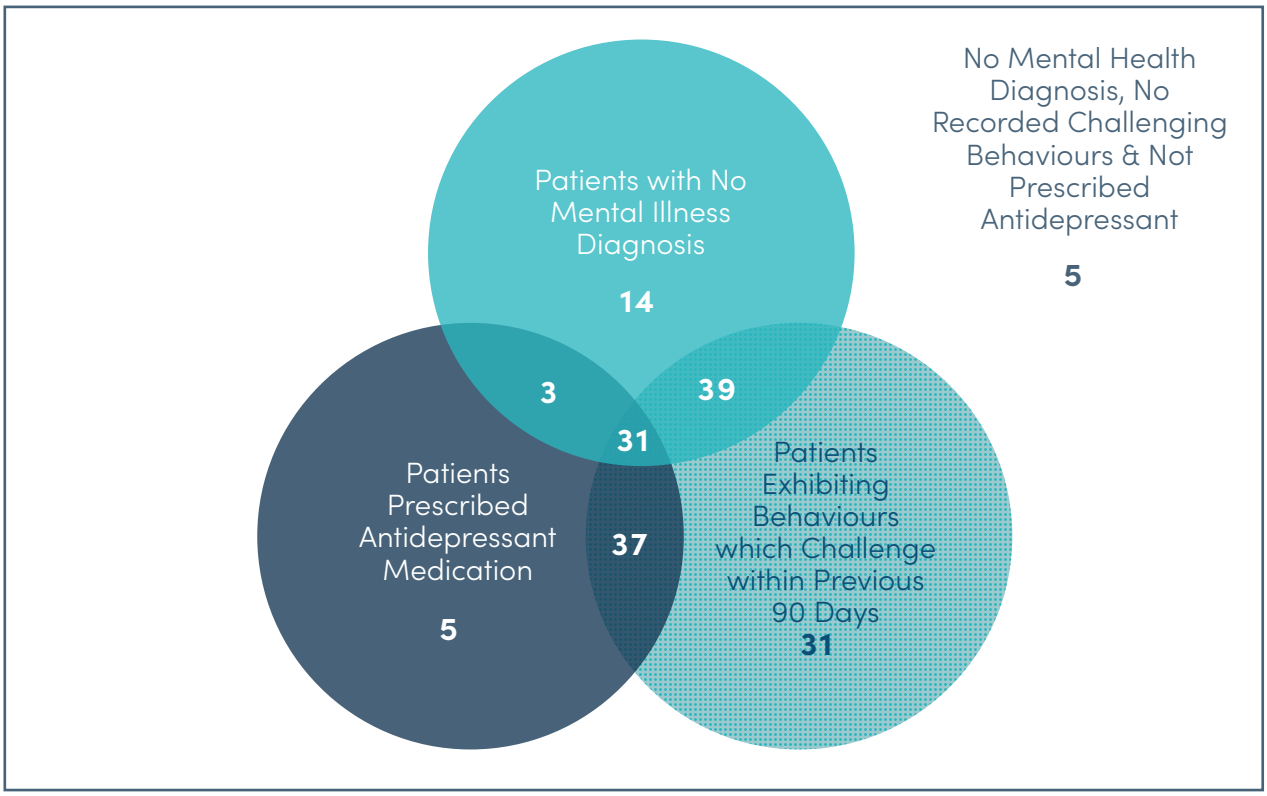


Studies have suggested that prescribing of antidepressants in the absence of diagnosed mental illness may be due to the '*limited published evidence*' supporting such prescriptions to alleviate the symptoms of obsessive–compulsive behaviour, aggression and anxiety.[95]

Figure 36 presents the overlap between those patients prescribed antidepressants, those patients with a mental illness and those patients exhibiting behaviours which challenge. The Figure shows that, of the 76 patients prescribed antidepressants, 68 (89%) had exhibited behaviours which challenge within the last ninety days and 76 (100%) had exhibited such behaviour since admission.

Figure 36:

Overlap Between Number of Patients Prescribed Antidepressants/ Exhibiting Behaviours That Challenge/With Mental Illness



As with all medications, regular review is vital and this National Care Review found that 64 patients (84%) had their prescriptions for antidepressant reviewed by a psychiatrist or GP within the previous twelve months.

18.3 Mood Stabilisers

Mood stabilisers are typically used for the treatment of manic–depressive spectrum conditions, or for the treatment of disruptive behaviours. Manic–depressive illness is '*occasionally seen*' in individuals with a learning disability, but misdiagnosis can occur as frequently such individuals can present with rapid alternations between excitement, irritability and high levels of activity, and withdrawal and loss of interest.[96]

This National Care Review found that overall 46 patients (28%) were prescribed mood stabilisers in some form, with 32 of the patients prescribed mood stabilisers being male and 14 being female. Thirty nine patients (85%) were prescribed a single mood stabiliser and 7 (15%) were prescribed more than one mood stabiliser; no mood stabilisers were prescribed to be administered 'as required'.

This National Care Review found that 17 (37%) of the 46 patients who were prescribed mood stabilisers had no recorded primary or secondary diagnosis of mental illness.

37%
Patients prescribed a mood stabiliser
WHERE THERE IS NO DIAGNOSIS OF MENTAL ILLNESS

Figure 37 presents the mood stabiliser prescription rate where there was a corresponding primary or secondary diagnosis of mental illness, by type of provider and gender. It shows, when considering those patients prescribed mood stabilisers, that males were more likely to not have a mental illness diagnosis (15, or 13%) than females (2, or 4%).

Figure 37:

Number of Patients Prescribed Mood Stabilisers With/Without Mental Illness

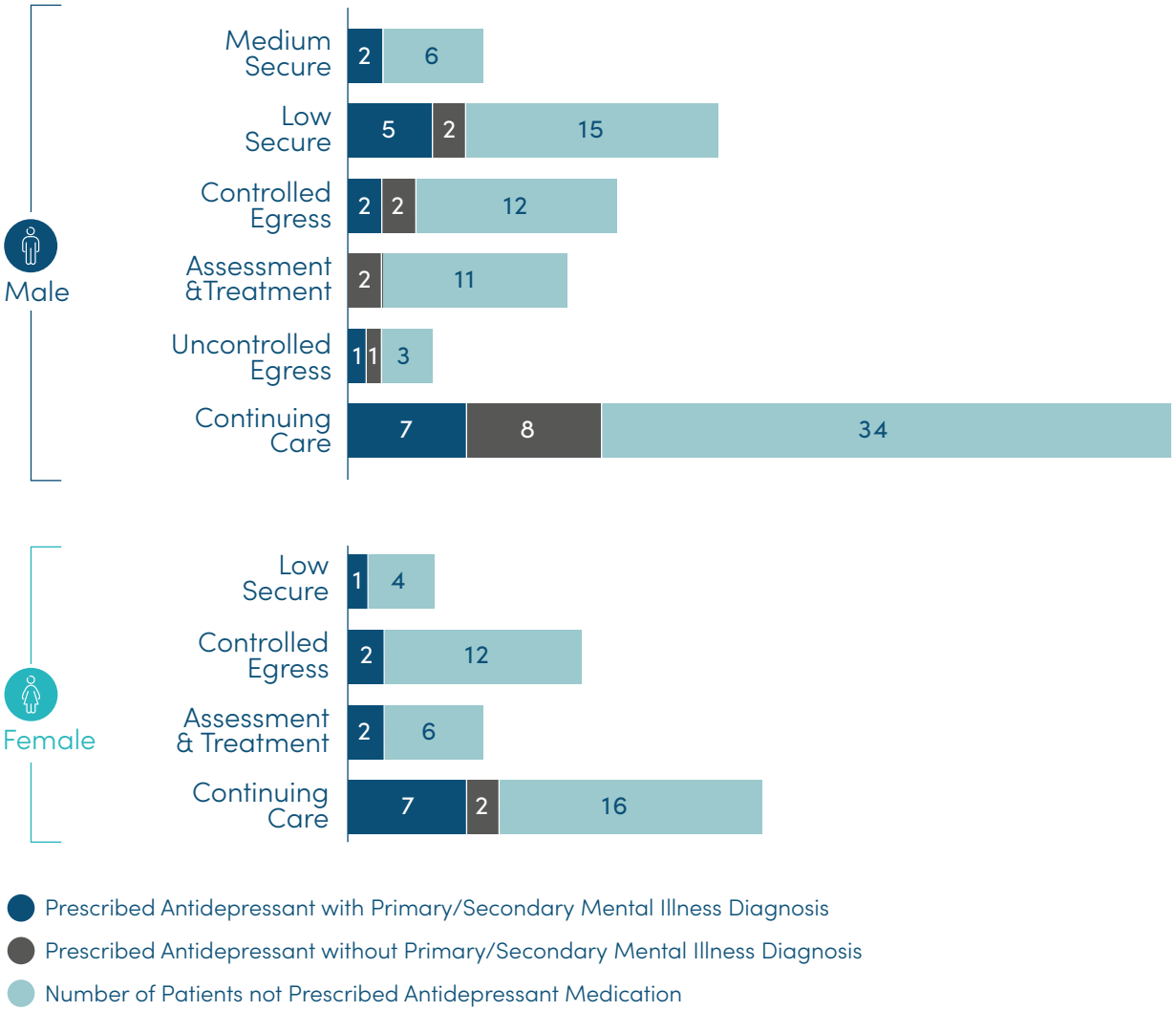
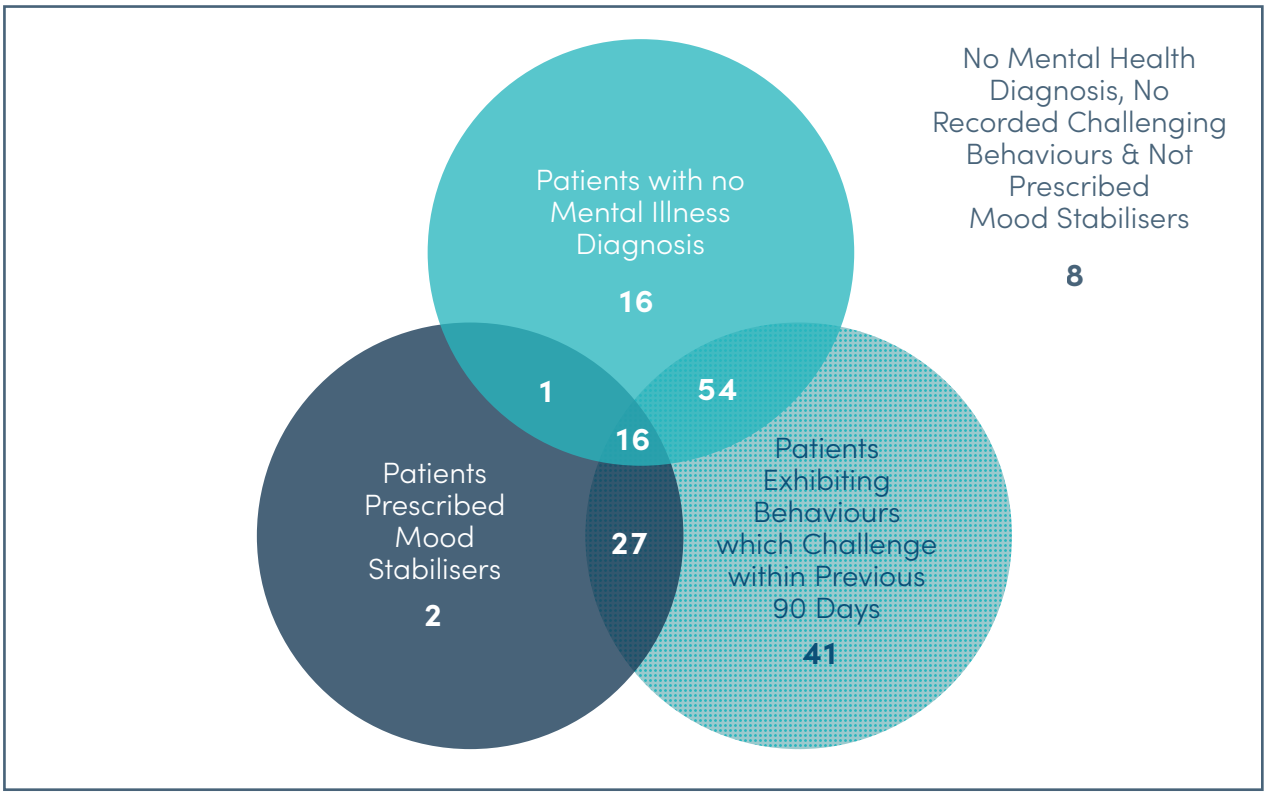


Figure 38 presents the overlap between those patients prescribed mood stabilisers, those patients with a mental illness and those patients exhibiting behaviours which challenge. The Figure shows that, of the 46 patients prescribed mood stabilisers, 43 (93%) had exhibited behaviours which challenged within the last ninety days and 46 (100%) had exhibited such behaviour since admission.

Figure 38:
Overlap Between Number of Patients Prescribed Mood Stabilisers Exhibiting Behaviours That Challenge/With Mental Illness



As with all medications, regular review is vital and this National Care Review found that 42 patients (91%) had their prescriptions for mood stabilisers reviewed by a psychiatrist or GP in the previous twelve months.

18.4 Anxiolytics, Sedatives & Hypnotics

Anxiolytics can be effective in alleviating anxiety, sedatives will induce sleep when given at night and most hypnotics will sedate when given during the day.

Studies have concluded that, in those individuals with a learning disability, the prevalence of anxiety disorders is estimated at 3%, and that of sleep disorders at 1%.[97]

After a patient has been prescribed this medication regularly for more than a few weeks, physical and psychological dependence can occur. Therefore, this medication type should be reserved for short courses to alleviate acute conditions after causal factors have been established.[98]

Studies have found anxiolytics/hypnotics prescription rates of 62% for individuals with a learning disability in hospitals.[99] This National Care Review found that overall 118 patients (72%) were prescribed anxiolytics, sedatives or hypnotics in some form, with 80 male patients and 39 female patients prescribed anxiolytics, sedatives or hypnotics. Figure 39 presents the form of anxiolytics, sedatives or hypnotics by the number and percentage of patients, by gender.

Figure 39:

Number of Patients Prescribed Anxiolytics, Sedatives or Hypnotic Medications

	Number of Patients		% of Patients	
	Male	Female	Male	Female
Not prescribed anxiolytics, sedatives or hypnotics in any form	33	13	29%	25%
Prescribed single anxiolytic, sedative or hypnotic	10	4	9%	7%
Prescribed single anxiolytics, sedatives or hypnotic and also one or more anxiolytic, sedative or hypnotic 'as required'	13	9	12%	17%
Prescribed single anxiolytic, sedative or hypnotic and also one or more anxiolytic, sedative or hypnotic as a regular injection (depot)	0	1	0	2%
Prescribed single anxiolytic, sedative or hypnotic and also one or more anxiolytic, sedative or hypnotic 'as required' and also one or more anxiolytic, sedative or hypnotic as a regular injection (depot)	6	0	5%	0
Prescribed more than one anxiolytic, sedative or hypnotic and also one or more anxiolytic, sedative or hypnotic 'as required'	14	5	12%	9%
Prescribed more than one anxiolytic, sedative or hypnotic and also one or more anxiolytic, sedative or hypnotic 'as required' and also one or more anxiolytic, sedative or hypnotic as a regular injection (depot)	4	1	4%	2%
Prescribed anxiolytics, sedatives or hypnotic 'as required' only	33	19	29%	36%
Total	**113**	**52**	**100%**	**100%**

Studies have found that 56% of patients with a learning disability who were prescribed hypnotics and 46% who were prescribed anxiolytics had no indicators of mental illness.[100]

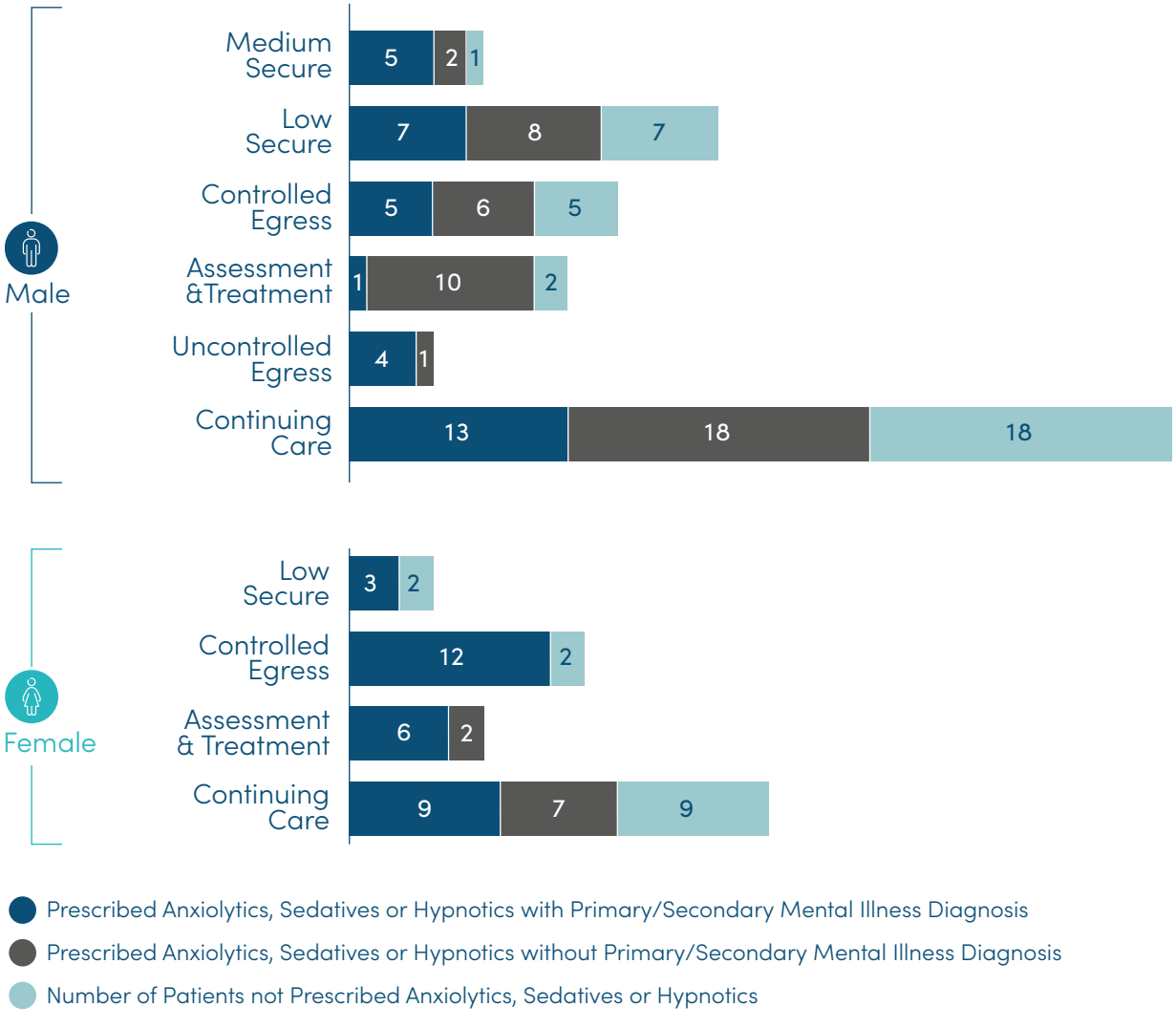
This National Care Review found that 54 (45%) of the 118 patients who were prescribed anxiolytics, sedatives or hypnotics had no recorded primary or secondary diagnosis of mental illness.

Figure 40 presents the anxiolytic, sedative or hypnotic prescription rate where there was a corresponding primary or secondary diagnosis of mental illness, by type of provider and gender. It shows, when considering those patients prescribed anxiolytics, sedatives or hypnotics, that males were more likely to not have a mental illness diagnosis (45, or 56%) than females (9, or 24%).

45%
Patients prescribed anxiolytics, sedatives or hypnotics
WHERE THERE WAS NO DIAGNOSIS OF MENTAL ILLNESS

Figure 40:

Number of Patients Prescribed Anxiolytics, Sedatives or Hypnotic Medications

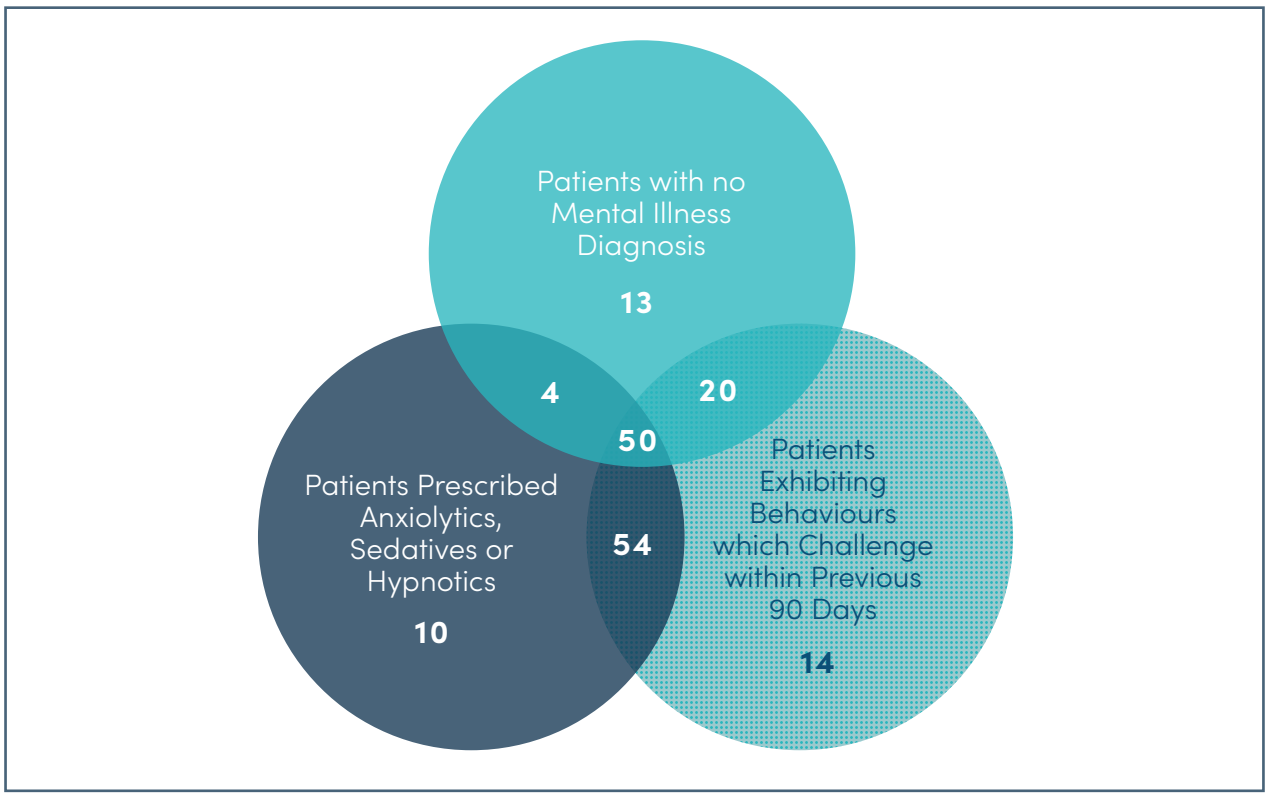


Studies have found that anxiolytics, sedatives or hypnotic are the '*most common*' class of drugs to be prescribed to manage behaviours that challenge.[101] Rates of prescribing these medications for behaviour which challenges have been reported as high as 59%.[102]

Figure 41 presents the overlap between those patients prescribed anxiolytics, sedatives or hypnotics, those patients with a mental illness and those patients exhibiting behaviours which challenge. The Figure shows that of the 118 patients prescribed anxiolytics, sedatives or hypnotics, 104 (88%) had exhibited behaviours which challenged within the last ninety days and 117 (99%) had exhibited such behaviour since admission.

Figure 41:

Overlap Between Number of Patients Prescribed Anxiolytics, Sedatives or Hypnotic Medication Exhibiting Behaviours That Challenge/With Mental Illness



As with all medications, regular review is vital and this National Care Review found that 96 patients (81%) had their prescriptions for anxiolytics, sedatives or hypnotics reviewed by a psychiatrist or GP within the previous twelve months.

18.5 Epilepsy Medication

Epilepsy is more commonly diagnosed in individuals with a learning disability than in the general population, *'about a third'* of individuals with a learning disability being diagnosed with epilepsy. The *'more severe'* the learning disability, the *'greater likelihood'* that the individual will also be diagnosed with epilepsy.[103]

As patients with a learning disability are at increased risk of epilepsy, it was not possible during this National Care Review to determine the primary use of antiepileptic medication. Using such medication for its mood-stabilizing effect as well as its anticonvulsant effect is '*commonplace*'.[104]

This National Care Review found that overall 41 patients (25%) were prescribed with medication, of whom 26 were male and 15 were female.

As with all medications, regular review is vital and this National Care Review found that 31 patients (76%) had their prescriptions for antiepileptic medication reviewed by a psychiatrist or GP within the previous twelve months.

18.6 Reducing the use of Psychotropic Medication

'Stopping the Over-Medication of People with Learning Disability, an Autistic Spectrum Disorder or Both' is a campaign launched in 2016 by NHS England, several Royal Colleges and medical societies. The campaign aims to minimise the use of psychotropic medication for individuals with learning disabilities and an autistic spectrum disorder, by promoting alternative approaches, regular review and a campaign of publicity and education for professionals. [105]

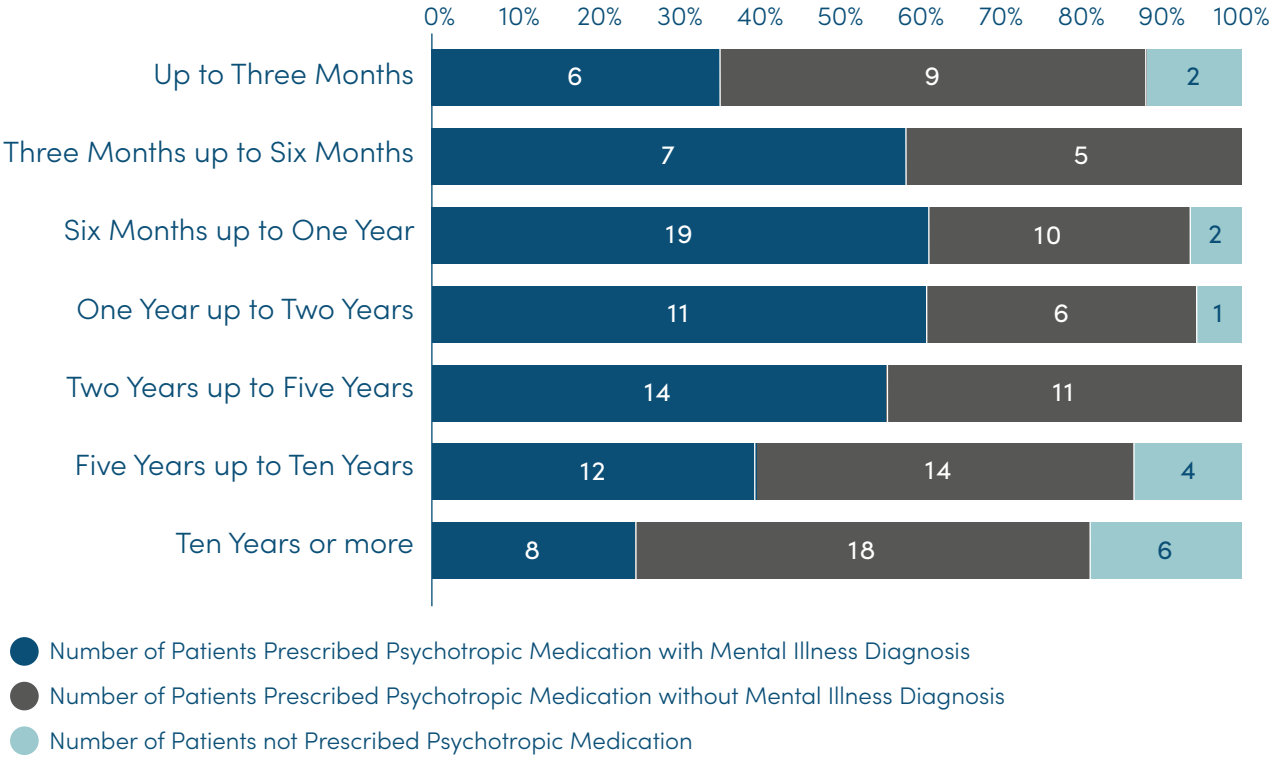
National standards state that patients should only be prescribed antipsychotic medication if they are also receiving psychological therapy or other therapies as part of their care.[106]

This National Care Review looked at the proportion of patients prescribed one or more psychotropic medications, whether the patient had a diagnosis of mental illness, and the patient's length of stay.

Figure 42 presents the number of patients with a mental illness diagnosis who were prescribed psychotropic medications, against length of stay.

Figure 42:

Psychotropic Prescribing & Mental Illness Diagnosis, by Length of Stay Time-bandings



Studies have found a wide variation in levels of training and knowledge regarding psychotropic medications amongst health professionals working with individuals with a learning disability.[107]

In many cases, communication issues make it difficult to secure informed consent for patients with learning disabilities to agree to be prescribed psychotropic medication. Therefore, compliance should never be mistaken for comprehension.[108]

Medications must be reviewed regularly and any lack of review should not be attributed to a lack of knowledge about alternatives, limited access to appropriate staff, or non-engagement in preventive programmes.[109]

It is Welsh Government policy to reduce inappropriate use of medication by increasing the use of a range of evidence-based interventions such as 'Positive Behavioural Support' and 'Active Support', to ensure early intervention for those individuals with a potential to exhibit behaviour which challenges.[110]

National Care Review Recommendations

23) Welsh Government should consider establishing a national campaign to support the reduction in the inappropriate use of psychotropic medication.
24) Providers should ensure all medication is prescribed at the minimum dosage to alleviate the verified symptoms.
25) Commissioners should ensure the adoption of evidence-based prescribing by all providers.
26) Providers should ensure that all medications are regularly reviewed for effectiveness and discontinued where efficacy is not demonstrated.
27) Providers must ensure that the patient, local care team and carers are involved in the decision to commence or discontinue any psychotropic medication.

19. Medication Side-Effects Monitoring

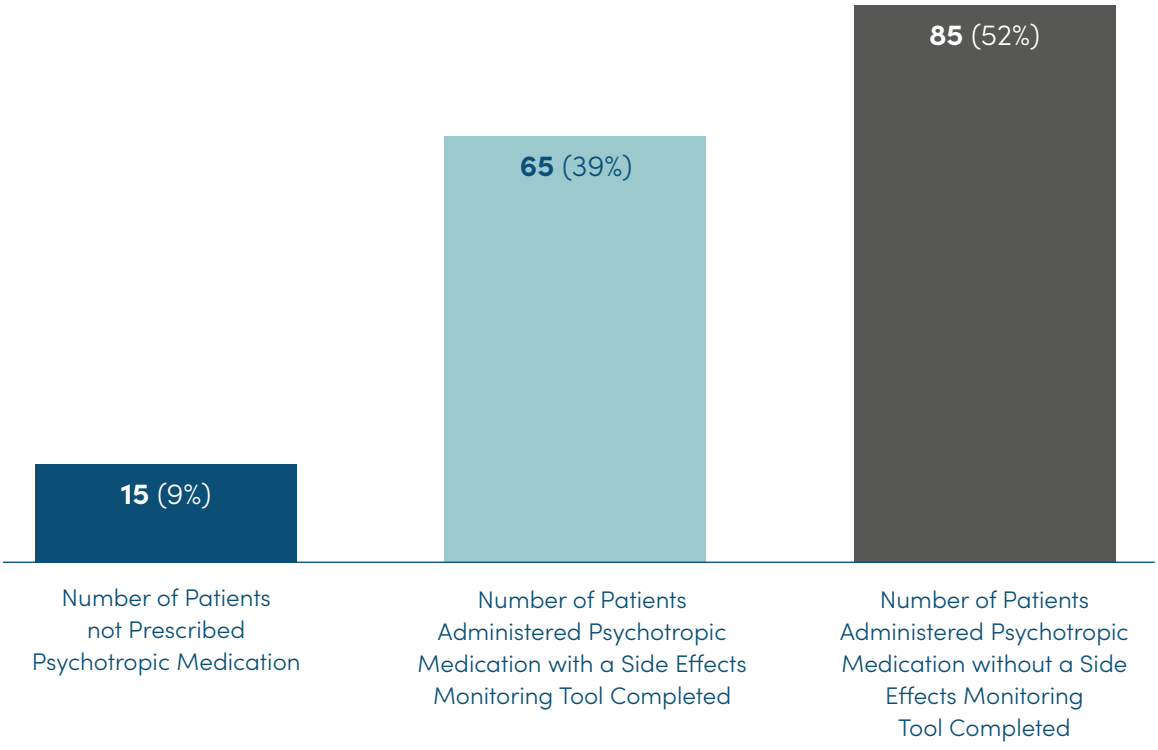
As well as potential benefits, many medications, including psychotropic medications, can have adverse side-effects that may have an impact on a individuals quality of life.[111]

Patients with a learning disability may be less likely to question a prescription, a change in the medication regime or potential side-effects, or to ask whether monitoring is required. This, together with the fact that some patients with a learning disability might have reduced capacity, places additional responsibilities on healthcare staff to monitor medication effects.[112]

Prescribed medication should be monitored regularly for efficacy, side effects, effect on physical health and impact on daily life. Monitoring can be carried out using specifically designed checklists, through questionnaires or by undertaking physical monitoring such as blood tests or electrocardiograms.

This National Care Review looked at whether a side-effects monitoring tool had been completed for those patients who had been prescribed a psychotropic medication. Figure 43 presents the number of patients who had been prescribed a psychotropic medication and a side-effects monitoring tool had been completed.

Figure 43:
Number of Patients Prescribed Psychotropic Medication with the use of a Side Effects Monitoring Tool



This National Care Review evidenced where a recognised tool such as a LUNSER [see box] had been used by staff[113], but the Review would not have detected where observations for potential side-effects had been undertaken without the use of a recognised tool.

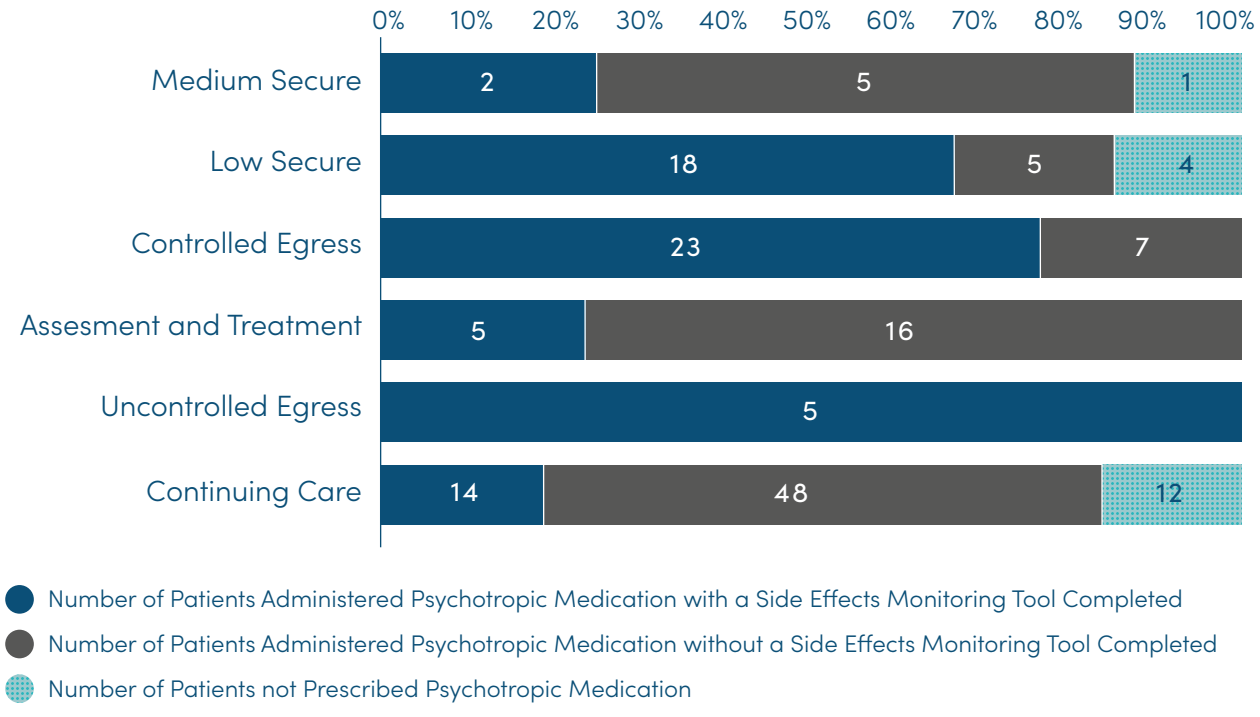
The issue of the safety and tolerability of medication is paramount for patients with learning disabilities, as they may have a different metabolism to that of the general population which may create different pharmacokinetics and pharmacodynamics.[114] Communication issues for individuals with a learning disability may make recognition of adverse effects problematic, therefore the use of side-effect monitoring tools remains an effective way to maximise the likelihood of detection of adverse effects or toxicity.

Figure 44 presents the number of patients where a psychotropic medication had been prescribed and a side-effects monitoring tool completed, by type of provider.

Liverpool University Side Effect Rating Scale.

The Liverpool University Side Effect Rating Scale (LUNSERS) is a rating scale which indicates the presence, severity and level of distress caused for each of the side effects listed. The tool has established reliability and validity and, although designed to be a self-rating scale, can be used for patients with a communication issues through questioning patient and/or their carers. No specific training is required by nurses to use the tool.

Figure 44:
Number of Patients Prescribed Psychotropic Medication with the Use of a Side Effects Monitoring Tool



The patient's past experience of adverse reactions should always be considered when prescribing medications.[115] Prescribers should regularly review medications for efficacy and side effects.[116] Staff administering medications have a responsibility for monitoring their effectiveness and their impact on functioning.

National Care Review Recommendations

28) Providers should ensure that all patients who are prescribed psychotropic medication have a recognised side effects monitoring tool completed.

29) Providers should ensure that patients and families receive information, in an accessible format, on desired effects and possible side-effects of medication.

20. Behaviours that Challenge

Behaviour can be described as challenging when it is of such an intensity, frequency, or duration as to threaten the quality of life or the physical safety of the individual or others and is likely to lead to responses that are restrictive.[117]

The term 'challenging behaviour' was introduced to move away from 'blaming the individual' towards describing behaviours as challenging to services, and to encourage professionals to find effective ways of understanding an individual's conduct and its underlying causes.[118] The term 'challenging behaviour' can be misused as a diagnostic label, leading to stigmatisation and exclusion.

When the frequency or intensity of behaviours that challenge results in a level of need and risk which cannot be effectively met in the community, admission to a hospital for assessment or treatment may be necessary as a last resort.[119]

Behaviour that challenges can include aggressive behaviour such as verbal threats and physical violence, destructive behaviour such as breaking or destroying furniture, disruptive behaviour such as repetitive screaming and smearing faeces, self-injurious behaviour such as self-biting and head banging and harmful sexual behaviour such as genitalia exposure and sexual assault.[120]

Behaviours that challenge have been reported to represent a form of communication, be caused by skills deficits, be associated with psychiatric disorder or physical illness, or to have been developed through operant conditioning.[121]

Studies have shown prevalence rates for behaviours that challenge of 10%–15% for individuals with a learning disability.[122] Prevalence rates of up to 40% have been reported in hospital settings, and even higher rates for patients who are young adults, diagnosed with an autistic spectrum disorder, or who have mental health problems or sensory impairments.[123] Comparisons across studies are difficult due to the inclusion/exclusion of certain behaviours.

This National Care Review identified the recorded frequency and intensity of behaviours that challenge within the following ten categories:

- Verbal aggression.
- Purposeful damage to property.
- Violent behaviour (no physical harm).
- Violent behaviour (causing harm).
- Deliberate self-harm.
- Absconded from hospital.
- Failed to return from leave.
- Sexually inappropriate behaviours.
- Harm from others (vulnerability).
- Other behaviour that challenges.

This National Care Review methodology included recording the intensity of incidents as 'no history', 'low intensity', 'medium intensity' and 'high intensity', and the frequency of these incidents as 'no history', 'historical with no record in last ninety days', 'once/twice in last 90 days', 'at least monthly', 'at least weekly' or 'at least daily'.

This National Care Review found that 156 patients (94%) had a historical or current record of one or more behaviours that challenge. Putting aside the historical record and looking only at the previous 90 days, 139 patients (84%) had exhibited one or more behaviours that challenge.

This National Care Review divided behaviours that challenge into two areas: 'behaviour towards others' such as verbal aggression, damage to property, sexually inappropriateness and violence; 'behaviour towards self' such as self-harm, absconding, harm from others.

84%

Patients exhibiting

ONE OR MORE BEHAVIOURS THAT CHALLENGE

within the previous ninety days

Figure 45 presents the number of patients with a historical or current (previous ninety days) record of 'behaviour towards others' or 'behaviour towards self' by gender. It shows that 75% of patients had exhibited one or more 'behaviours towards others' and 41% of patients had exhibited one or more 'behaviours towards self', within the previous ninety days.

Figure 45:

Number of Patients with Current or Historical Behaviour Which Challenges By Gender

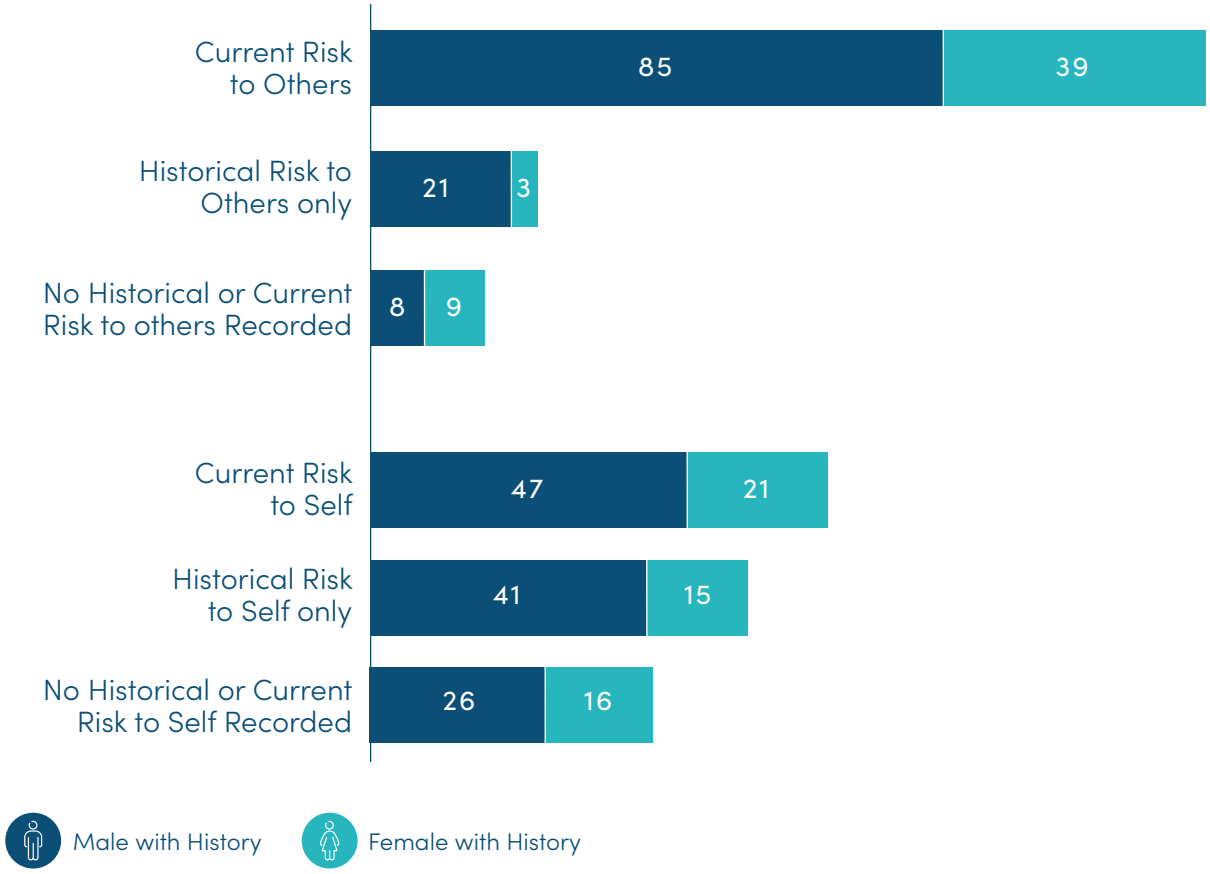
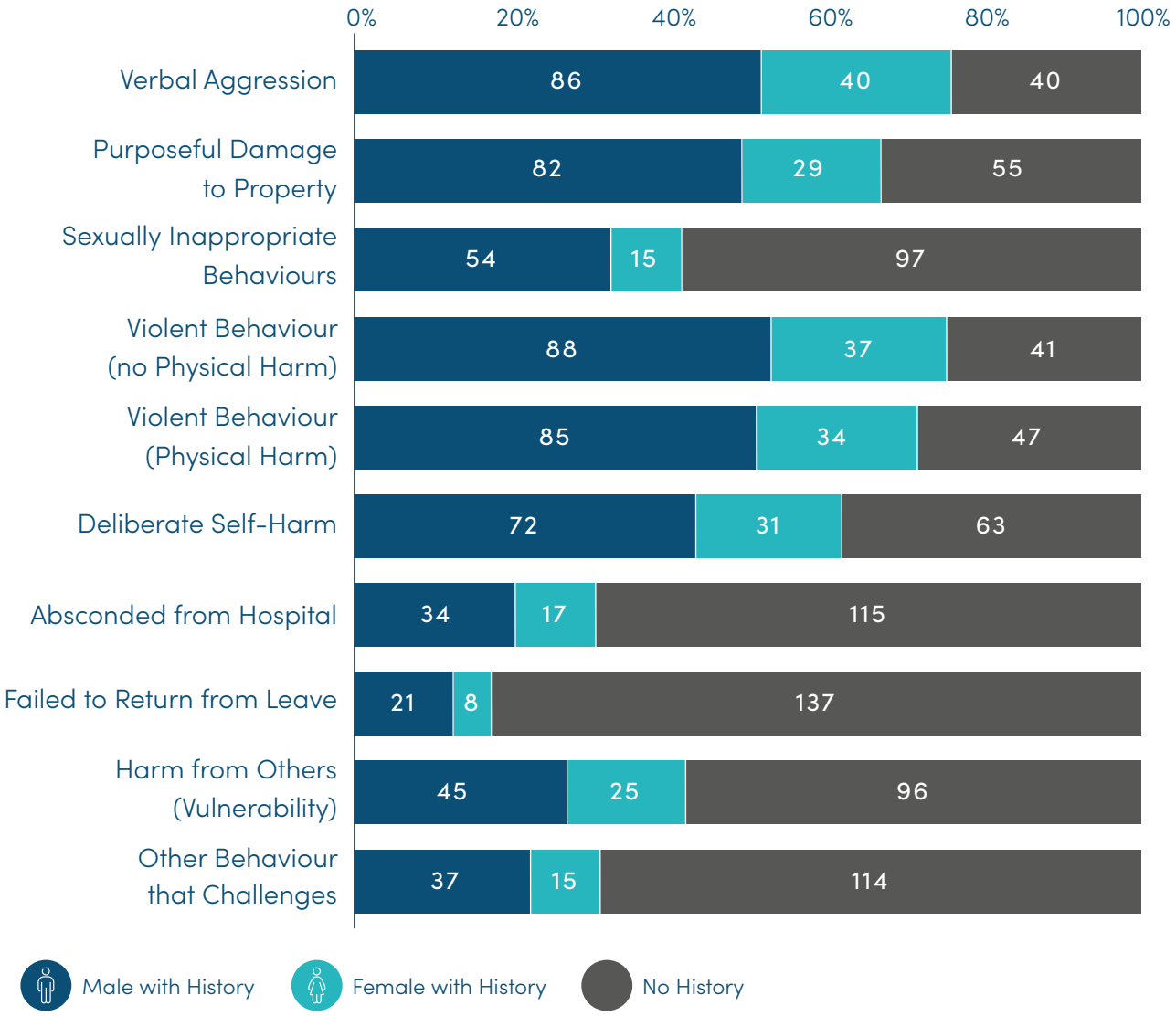


Figure 46 presents the number of patients with a historical or current history across the ten individual 'behaviour that challenge' categories, by gender.

Figure 46:

Number of Patients with Specific Behaviours Which Challenges by Gender



Behaviours that challenge may present only in certain environments, as some units are noisy, crowded, unresponsive or unpredictable. Behaviours that challenge may be used by some patients to create sensory stimulation or gain assistance.[124]

20.1 Verbal Aggression

Behaviour: The patient shouting, swearing, screaming and generally exhibiting verbal aggression towards others.

This National Care Review found that 126 patients (76%) had a history of verbal aggression towards others at any time across all types of provider, and 102 (61%) of these patients had exhibited this behaviour in the previous 90 days. Figure 47 presents the number of patients exhibiting verbal aggression towards others, by intensity and frequency. It shows that the most common occurrence of this behaviour is the weekly exhibiting of low intensity verbal aggression.

Figure 47:
Number of Patients Exhibiting Verbal Aggression by Frequency & Intensity

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
No History	40 (24%)					
Low Intensity		21 (13%)	16 (10%)	9 (5%)	35(21%)	10 (6%)
Medium Intensity		3 (2%)	5 (3%)	3 (2%)	11 (7%)	11 (7%)
High Intensity					1 (1%)	1 (1%)

The reason specific types of provider, like medium secure or uncontrolled egress, are preferred to others is complex, but one of the reasons is the nature and degree of behaviours that challenge. Staff numbers, experience and skills, and the environment of care all contribute to the effective management of behaviours that challenge.

Figure 48 presents the number of patients exhibiting verbal aggression towards others, by type of provider, and shows that patients cared for in medium secure units or uncontrolled egress units were most likely (100%) to have a history of verbal aggression, and those in continuing care units least likely (59%).

Figure 48:

Number of Patients Exhibiting Verbal Aggression by Frequency & Type of Provider

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Medium Secure		1 (13%)	2 (25)		4 (50%)	1 (13%)
Low Secure	2 (7%)	3 (11%)	6 (21%)	5 (18%)	11 (39%)	1 (4%)
Controlled Egress	2 (7%)	6 (20%)	7 (23%)	2 (7%)	12 (40%)	1 (3%)
Assessment & Treatment	6 (29%)		2 (10%)	2 (10%)	6 (29%)	5 (24%)
Uncontrolled Egress		2 (40%)	1 (20%)	1 (20%)	1 (20%)	
Continuing Care	30 (41%)	12 (16%)	3 (4%)	2 (3%)	13 (18%)	14 (19%)

Studies have suggested that female patients with learning disabilities experience higher levels of anger than males and also demonstrate difficulties in regulating anger.[125] Figure 49 presents the number of patients exhibiting verbal aggression towards others, by gender, and shows that female patients were more likely (40, or 77%) to have a history of this behaviour than male patients (86, or 75%).

Figure 49:

Number of Patients Exhibiting Verbal Aggression by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	28 (25%)	19 (17%)	14 (12%)	12 (11%)	27 (24%)	14 (12%)
Female	12 (23%)	5 (10%)	6 (12%)		21 (40%)	8 (15%)

20.2 Purposeful Damage to Property

Behaviour: The patient breaking, or otherwise damaging, furniture, fixtures and appliances.

This National Care Review found that 111 patients (67%) had a history of damaging property purposefully, at any time across all care types, and 59 (36%) of these patients had exhibited this behaviour in the previous ninety days. Studies in Scotland found that 40 % of patients had recently damaged property purposefully.[126]

Figure 50 presents the number of patients damaging property purposefully, by intensity and frequency, and shows that the most common occurrence is the historical record of low intensity damage to property.

Figure 50:

Number of Patients Damaging Property Purposefully by Frequency & Intensity

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
No History	55 (33%)					
Low Intensity		27 (16%)	4 (2%)	5 (3%)	5 (3%)	1 (1%)
Medium Intensity		15 (9%)	14 (8%)	18 (11%)	9 (5%)	2 (1%)
High Intensity		10 (6%)	1 (1%)			

The reason specific types of provider, like medium secure or uncontrolled egress, are preferred to others is complex, but one of the reasons is the nature and degree of behaviours that challenge. The environment of care, durability of furniture and accessibility of appliances all contribute to the effective management of behaviours that challenge.

Figure 51 presents the number of patients damaging property purposefully, by type of provider, and shows that patients cared for in medium secure units or uncontrolled egress units were more likely (100%), and those in continuing care units less likely (54%), to have a history of damaging property purposefully than those in other types of provider.

Figure 51:

Number of Patients Damaging Property Purposefully by Frequency & Type of Provider

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Medium Secure		4 (50%)		2 (25%)	2 (25%)	
Low Secure	10 (36%)	10 (36%)	2 (7%)	2 (7%)	3 (11%)	1 (4%)
Controlled Egress	4 (13%)	12 (40%)	8 (27%)	5 (7%)	1 (3%)	
Assessment & Treatment	7 (33%)	5 (24%)	3 (14%)	4 (19%)	2 (10%)	
Uncontrolled Egress		2 (40%)	2 (40%)	1 (20%)		
Continuing Care	34 (46%)	19 (26%)	4 (5%)	9 (12%)	6 (8%)	2 (3%)

Figure 52 shows the number of patients damaging property purposefully, by gender, and shows that male patients were more likely (82, or 72%) to present this behaviour than female patients (29, or 56%).

Figure 52:

Number of Patients Damaging Property Purposefully by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	32 (28%)	43 (38%)	10 (9%)	16 (14%)	11 (10%)	2 (2%)
Female	23 (44%)	9 (17%)	9 (17%)	7 (13%)	3 (6%)	1 (2%)

20.3 Violent Behaviour, No Physical Harm

Behaviour: Patient pushing and grabbing others but causing no physical injury.

This National Care Review found that 125 patients (75%) had a history of violent behaviour, but causing no physical harm, at any time across all care types and 86 (52%) of these patients had exhibited this behaviour in the previous ninety days. Studies in Scotland found that 55% of patients had recently exhibited physical aggression.[127]

Figure 53 presents the number of patients exhibiting violent behaviour, by intensity and frequency, and shows that the most common occurrence is the historical record of low intensity violent behaviour but causing no physical harm.

Figure 53:

Number of Patients Exhibiting Violent Behaviour – No Harm by Frequency & Intensity

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
No History	41 (25%)					
Low Intensity		30 (18%)	20 (12%)	13 (8%)	8 (5%)	7 (4%)
Medium Intensity		5 (2%)	9 (5%)	8 (5%)	12 (7%)	7 (4%)
High Intensity		4 (2%)		1 (1%)	1 (1%)	

The reason specific types of provider, like medium secure or uncontrolled egress, are preferred to others is complex, but one of the reasons is the nature and degree of behaviours that challenge. The skills, experience and numbers of staff all contribute to the effective management of behaviours that challenge.

Figure 54 presents the number of patients exhibiting violent behaviour but causing no physical harm, by type of provider, and shows that patients cared for in uncontrolled egress units were more likely (100%) and those in continuing care units less likely (69%), to have a history of violent behaviour, but causing no physical harm, than those in other types of provider.

Figure 54:

Number of Patients Exhibiting Violent Behaviour - No Harm by Frequency & Type of Provider

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Medium Secure	1 (13%)	4 (50%)	2 (25%)	2 (25%)		1 (13%)
Low Secure	5 (18%)	9 (32%)	4 (14%)	7 (25%)	3 (11%)	
Controlled Egress	8 (27%)	6 (20%)	6 (20%)	6 (20%)	3 (10%)	1 (3%)
Assessment & Treatment	4 (19%)	1 (5%)	6 (29%)	2 (10%)	5 (24%)	3 (14%)
Uncontrolled Egress		2 (40%)	3 (60%)			
Continuing Care	23 (31%)	17 (23%)	8 (11%)	7 (9%)	10 (14%)	9 (12%)

Figure 55 presents the number of patients exhibiting violent behaviour but causing no physical harm, by gender, and shows that male patients were more likely (88, or 77%) to have a history of this behaviour than female patients (37, or 71%).

Figure 55:

Number of Patients Exhibiting Violent Behaviour - No Harm by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	26 (23%)	32 (28%)	19 (17%)	14 (12%)	13 (11%)	10 (9%)
Female	15 (29%)	7 (13%)	10 (19%)	8 (15%)	8 (15%)	4 (8%)

20.4 Violent Behaviour, Causing Harm

Behaviour: The patient punching, biting, kicking, pulling and pushing others and causing physical Injury.

This National Care Review found that 119 patients (72%) had a history of exhibiting violent behaviour, causing harm, at any time across all care types, and that 70 (42%) of these patients had exhibited this behaviour in the previous ninety days.

Figure 56 presents the number of patients exhibiting violent behaviour, causing harm, by intensity and frequency, and shows that the most common occurrence is the historical record of medium intensity violent behaviour, causing harm.

Figure 56:

Number of Patients Exhibiting Violent Behaviour - Harm by Frequency & Intensity

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
No History	47 (28%)					
Low Intensity		13 (8%)	4 (2%)	6 (4%)	1 (1%)	
Medium Intensity		23 (14%)	13 (8%)	15 (9%)	15 (9%)	5 (3%)
High Intensity		13 (8%)	2 (1%)	5 (3%)	2 (1%)	2 (1%)

The reason specific types of provider, like medium secure or uncontrolled egress, are preferred to others is complex, but one of the reasons is the nature and degree of behaviours that challenge. The skills, experience and numbers of staff all contribute to the effective management of behaviours that challenge.

Figure 57 presents the number of patients exhibiting violent behaviour, causing harm, by type of provider, and shows that patients cared for in uncontrolled egress units were more likely (100%), and those in low secure units and continuing care units less likely (68%) to have a history of violent behaviour, causing harm, than those in other types of provider.

Figure 57:

Number of Patients Exhibiting Violent Behaviour - Harm by Frequency & Type of Provider

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Medium Secure	1 (13%)	4 (50%)	1 (13%)	2 (25%)		
Low Secure	9 (32%)	9 (32%)	4 (14%)	3 (11%)	3 (11%)	
Controlled Egress	8 (27%)	8 (27%)	3 (10%)	7 (23%)	3 (10%)	1 (3%)
Assessment & Treatment	5 (24%)	3 (14%)	3 (14%)	3 (14%)	5 (24%)	2 (10%)
Uncontrolled Egress		3 (60%)	2 (40%)			
Continuing Care	24 (32%)	22 (30%)	6 (8%)	11 (15%)	7 (9%)	4 (5%)

Figure 58 presents the number of patients exhibiting violent behaviour causing harm, by gender, and shows that male patients were more likely (85, or 75%) to have a history of this behaviour than female patients (34, or 65%).

Figure 58:

Number of Patients Exhibiting Violent Behaviour - Harm by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	29 (25%)	36 (32%)	16 (14%)	16 (14%)	12 (11%)	5 (4%)
Female	18 (35%)	13 (25%)	3 (6%)	10(19%)	6 (11%)	2 (4%)

20.5 Deliberate Self-Harm

Behaviour: The patient biting, hitting, pulling own hair, falling to the floor or banging their heads causing physical injury to themselves.

Deliberate self-harm is very common in individuals who have a learning disability. Sometimes this behaviour is transitory and short in duration, lasting only days or weeks, while at other times it can persist for months or years.[128]

This National Care Review found that 103 patients (62%) had a history of deliberate self-harm, at any time across all care types, and 59 (36%) of these patients had exhibited this behaviour in the previous 90 days. Studies in Scotland found that 31% of hospital patients had self-harmed recently.[129]

Figure 59 presents the number of patients deliberately self-harming, by intensity and frequency, and shows that the most common occurrence is the historical record of low intensity deliberate self-harm.

Figure 59:
Number of Patients Deliberately Self-Harming by Frequency & Intensity

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
No History	63 (38%)					
Low Intensity		22 (13%)	3 (2%)	1 (1%)	4 (2%)	1 (1%)
Medium Intensity		16 (10%)	10 (6%)	14 (8%)	9 (5%)	10 (6%)
High Intensity		8 (5%)	1 (1%)	1 (1%)	1 (1%)	2 (1%)

The reason specific types of provider, like medium secure units or uncontrolled egress units, are preferred to others is complex, but one of the reasons is the nature and degree of behaviours that challenge. The skills, experience and numbers of staff all contribute to the effective management of behaviours that challenge. Self-harming behaviour is '*extremely difficult*' to manage because it is resistant to behavioural change interventions.[130]

Figure 60 presents the number of patients deliberately self-harming, by type of provider, and shows that patients cared for in medium secure units were more likely (100%), and those in continuing care units less likely (55%), to have a history of deliberate self-harm than in other types of provider.

Figure 60:

Number of Patients Deliberately Self-Harming by Frequency & Type of Provider

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Medium Secure		5 (63%)	1 (13%)	2 (25%)		
Low Secure	11 (39%)	10 (36%)	2 (7%)		4 (14%)	1 (4%)
Controlled Egress	10 (33%)	10 (33%)	3 (10%)	5 (17%)	1 (3%)	1 (3%)
Assessment & Treatment	8 (38%)	2 (10%)	3 (14%)	3 (14%)	3 (14%)	2 (10%)
Uncontrolled Egress	1 (20%)	2 (40%)	1 (20%)	1 (20%)		
Continuing Care	33 (45%)	17 (23%)	4 (5%)	5 (7%)	6 (8%)	9 (12%)

Figure 61 presents the number of patients deliberately self-harming, by gender, and shows that male patients were more likely (72, or 63%) to have a history of this behaviour than female patients (31, or 60%).

Figure 61:

Number of Patients Deliberately Self-Harming by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	42 (37%)	33 (29%)	10 (9%)	10 (9%)	9 (8%)	10 (9%)
Female	21 (40%)	13 (25%)	4 (8%)	6 (12%)	5 (10%)	3 (6%)

20.6 Absconded from Hospital

Behaviour: The patient is absent without permission from the hospital or leaves the hospital without notifying staff.

Patients who abscond are at greater risk of self-harm, self-neglect, missed medication, and interruptions to their treatment.[131]

This National Care Review found that 51 patients (31%) had a history of absconding at any time across all types of providers, and that six patients (4%) had exhibited this behaviour in the previous ninety days.

Figure 62 presents the number of patients who had absconded, by intensity and frequency, and shows that the most common occurrence is the historical record of low intensity absconding.

Figure 62:
Number of Patients Absconding by Frequency & Intensity

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
No History	115 (69%)					
Low Intensity		41 (25%)	4 (2%)	1 (1%)		
Medium Intensity		2 (1%)	1 (1%)			
High Intensity		2 (1%)				

The reason specific types of provider, like medium secure units or uncontrolled egress units, are preferred to others is complex, but one of the reasons is the nature and degree of behaviours that challenge. The environment of care, especially in units with locked doors or perimeter fences, can actively obstruct absconding.

Figure 63 presents the number of patients who had absconded by type of provider and shows that patients cared for in uncontrolled egress units were more likely (80%), and those in low secure units less likely (21%), to have a history of absconding than those in other types of provider.

Figure 63:

Number of Patients Absconding by Type of Provider

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Medium Secure	5 (63%)	2 (25%)	1 (13%)			
Low Secure	22 (79%)	6 (21%)				
Controlled Egress	21 (70%)	8 (27%)	1 (3%)			
Assessment & Treatment	14 (67%)	5 (24%)	2 (10%)			
Uncontrolled Egress	1 (20%)	4 (80%)				
Continuing Care	52 (70%)	20 (27%)	1 (1%)	1 (1%)		

Figure 64 presents the number of patients who had absconded, by gender, and shows that female patients were more likely (17, or 33%) to have a history of this behaviour than male patients (34, or 30%).

Figure 64:

Number of Patients Absconding by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	80 (70%)	29 (25%)	4 (4%)	1 (1%)		
Female	35 (67%)	16 (31%)	1 (2%)			

20.7 Failed to Return From Leave

Behaviour: The patient fails to return from leave or absconds from escorts whilst on community leave.

This National Care Review found that 29 patients (17%) had a history of failing to return from leave, across all types of provider. One patient (1%) had exhibited this behaviour in the previous 90 days.

Figure 65 presents the number of patients failing to return from leave, by intensity and frequency, and shows that the most common occurrence is the historical record of low intensity failing to return from leave.

Figure 65:

Number of Patients Failing to Return From Leave by Frequency & Intensity

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
No History	137 (83%)					
Low Intensity		26 (16%)	1 (1%)			
Medium Intensity		1 (1%)				
High Intensity		1 (1%)				

The reason specific types of provider, like medium secure units or uncontrolled egress units, are preferred to others is complex, but one of the reasons is the nature and degree of behaviours that challenge. The skills, experience and numbers of staff all contribute to the effective management of behaviours that challenge.

Figure 66 presents the number of patients who had failed to return from leave, by type of provider, and shows that patients cared for in uncontrolled egress units were more likely (80%), and those in controlled egress units less likely (3%), to have failed to return from leave than those in other types of provider.

Figure 66:

Number of Patients Failing to Return from Leave by Frequency & Type of Provider

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Medium Secure	5 (62%)	3 (38%)				
Low Secure	21 (75%)	6 (21%)	1 (1%)			
Controlled Egress	29 (97%)	1 (3%)				
Assessment & Treatment	18 (86%)	3 (14%)				
Uncontrolled Egress	1 (20%)	4 (80%)				
Continuing Care	63 (85%)	11 (15%)				

Figure 67 presents the number of patients who had failed to return from leave, by gender, and shows that male patients were more likely (21 or 18%) to have a history of this behaviour than female patients (8 or 15%).

Figure 67:

Number of Patients Failing to Return From Leave by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	93 (82%)	20 (18%)	1 (1%)			
Female	44 (85%)	8 (15%)				

20.8 Sexually Inappropriate Behaviours

Behaviour: The patient is sexually disinhibited or sexually aggressive towards others.

Patients with learning disabilities, especially males, may expose themselves or touch others sexually when this is not wanted.[132]

This National Care Review found that 69 patients (42%) had a history of sexually inappropriate behaviour and that 28 patients (17%) had exhibited this behaviour in the previous ninety days. Studies in Scotland found that 18% of hospital patients had exhibited sexually inappropriate behaviour recently[133].

Figure 68 presents the number of patients who had exhibited sexually inappropriate behaviour, by intensity and frequency, and shows that the most common occurrence is the historical record of low intensity sexually inappropriate behaviour.

Figure 68:
Number of Patients Exhibiting Sexually Inappropriate Behaviour by Frequency & Intensity

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
No History	97 (58%)					
Low Intensity		28 (17%)	11 (7%)	3 (2%)	4 (2%)	4 (2%)
Medium Intensity		9 (5%)	1 (1%)	1 (1%)	3 (2%)	1 (1%)
High Intensity		4 (2%)				

The reason specific types of providers, like medium secure units or uncontrolled egress units, are preferred to others is complex, but one of the reasons is the nature and degree of behaviours that challenge. The skills, experience and numbers of staff all contribute to the effective management of behaviours that challenge.

Figure 69 presents the number of patients who had exhibited sexually inappropriate behaviour, by type of provider, and shows that patients cared for in uncontrolled egress units were more likely (100%), and those in assessment and treatment units less likely (24%), to have a history of sexually inappropriate behaviour than those in other types of provider.

Figure 69:

Number of Patients Exhibiting Sexually Inappropriate Behaviour by Frequency & Type of Provider

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Medium Secure	3 (38%)	3 (38%)	1 (13%)		1 (13%)	
Low Secure	11 (39%)	10 (36%)	3 (11%)	3(11%)	1 (4%)	
Controlled Egress	15 (50%)	11 (37%)	2 (7%)		1 (3%)	1 (3%)
Assessment & Treatment	16 (76%)	3 (14%)	1 (5%)			1 (5%)
Uncontrolled Egress		4 (80%)		1 (20%)		
Continuing Care	52 (70%)	10 (14%)	5 (7%)		4 (5%)	3 (4%)

Figure 70 presents the number of patients who had exhibited sexually inappropriate behaviour, by gender, and shows that male patients were more likely (54 or 47%) to have a history of this behaviour than female patients (15 or 29%).

Figure 70:

Number of Patients Exhibiting Sexually Inappropriate Behaviour by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	60 (53%)	33 (29%)	9 (8%)	3 (3%)	5 (4%)	4 (4%)
Female	37 (71%)	8 (15%)	3 (6%)	1 (2%)	2 (4%)	1 (2%)

20.9 Harm From Others (Vulnerability)

Behaviour: The patient suffers verbal threats, bullying or assault from others.

This National Care Review found that 70 patients (42%) had suffered harm from others, at any time across all types of providers, and 21 patients (13%) had suffered harm from others in the previous ninety days.

Figure 71 presents the number of patients who had suffered harm from others, by intensity and frequency, and shows that the most common occurrence is the historical record of patients who had suffered medium intensity between suffered and harm from others.

Figure 71:

Number of Patients Suffering Harm from Others by Frequency & Intensity

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
No History	96 (58%)					
Low Intensity			1 (1%)	2 (1%)	1 (1%)	
Medium Intensity		42 (25%)	15 (9%)	1 (1%)	1 (1%)	
High Intensity		7 (4%)				

The reason specific types of provider, like medium secure or uncontrolled egress, are preferred to others is complex, but one of the reasons is the skills, experience and numbers of staff to maintain a safe environment of care.

Figure 72 presents the number patients who had suffered harm from others, by type of provider, and shows that patients cared for in controlled egress units and uncontrolled egress units were more likely (60%) to have suffered harm from others than in other types of provider.

Figure 72:

Number of Patients Suffering Harm from Others by Frequency & Type of Provider

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Medium Secure	4 (50%)	3 (38%)	1 (13%)			
Low Secure	16 (57%)	10 (36%)	1 (4%)	1 (4%)		
Controlled Egress	12 (40%)	11 (37%)	7 (23%)			
Assessment & Treatment	12 (57%)	5 (24%)	4 (19%)			
Uncontrolled Egress	2 (40%)	2 (40%)	1 (20%)			
Continuing Care	50 (68%)	18 (24%)	2 (3%)	2 (3%)	2 (3%)	

Figure 73 presents the number of patients who had suffered harm from others, by gender, and shows that female patients were more likely (25 or 48%) to have a history of this than male patients (45 or 39%).

Figure 73:

Number of Patients Suffering Harm from Others by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	69 (61%)	33 (29%)	9 (8%)	2 (2%)	1 (1%)	
Female	27 (52%)	16 (31%)	7 (13%)	1 (2%)	1 (2%)	

20.10 Other Behaviour That Challenges

Behaviour: The patient smears faeces, urinates and exhibits other behaviours which disrupts the unit milieu.

This National Care Review found that 52 patients (31%) had a history of 'other' behaviour that challenges, at any time across all types of provider and 31 patients (19%) had exhibited this behaviour in the previous ninety days.

Figure 74 presents the number of patients who had exhibited 'other' behaviour that challenges, by intensity and frequency, and shows that the most common occurrence is the historical record of low intensity 'other' behaviour.

Figure 74:
Number of Patients Exhibiting Other Behaviour That Challenges by Frequency & Intensity

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
No History	114 (69%)					
Low Intensity		14 (8%)	6 (4%)	1 (1%)		2 (1%)
Medium Intensity		3 (2%)	7 (4%)	1 (1%)	6 (4%)	2 (1%)
High Intensity		4 (2%)	2 (1%)	1 (1%)	1 (1%)	2 (1%)

The reason specific types of provider, like medium secure units or uncontrolled egress units, are preferred to others is complex, but one of the reasons is the nature and degree of behaviours that challenge. The skills, experience and numbers of staff all contribute to the effective management of behaviours that challenge.

Figure 75 presents the number of patients who had exhibited 'other' behaviour that challenges, by type of provider, and shows that patients cared for in assessment and treatment units were more likely (52%), and those in uncontrolled egress units less likely (20%), to have a history of 'other' behaviour that challenges than those in other types of providers.

Figure 75:

Number of Patients Exhibiting Other Behaviour That Challenges by Frequency & Type of Provider

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Medium Secure	4 (50%)	2 (25%)	2 (25%)			
Low Secure	20 (71%)	4 (14%)			2 (7%)	2 (7%)
Controlled Egress	18 (60%)	8 (27%)	2 (7%)		1 (3%)	1 (3%)
Assessment & Treatment	10 (48%)	3 (14%)	6 (29%)		1 (5%)	1 (5%)
Uncontrolled Egress	4 (80%)	1 (20%)				
Continuing Care	58 (78%)	3 (4%)	5 (7%)	3 (4%)	3 (4%)	2 (3%)

Figure 76 presents the number of patients who had exhibited 'other' behaviour that challenges, by gender, and shows that male patients were more likely (37 or 32%) to have a history of this behaviour than female patients (15 or 29%).

Figure 76:

Number of Patients Exhibiting Other Behaviour that Challenges by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	77 (68%)	15 (13%)	11 (10%)	3 (3%)	5 (4%)	3 (3%)
Female	37 (71%)	6 (12%)	4 (8%)	1 (2%)	2 (4%)	3 (6%)

20.11 Impact On Staff

An NHS survey reported that '*two thirds*' of learning disability nurses and support workers had experienced physical violence from patients.[134] Supporting individuals with learning disabilities and behaviours which challenge can be stressful and emotionally challenging for staff.[135]

20.12 Reducing Behaviours Which Challenge

Individuals with a learning disability and behaviours that challenge should get the assessments and treatments they need in the community, and if they require admission to hospital it should be for the shortest period.[136]

Many patients remain hospitalised because of risks which are historical, not current, and these risks require balancing with the risk to the patient's independence of a continued inpatient stay.[137]

As stated previously, this National Care Review divides behaviours that challenge into those which pose a risk to the patient themselves and behaviours which pose a risk to others. Figure 77 presents the number of patients who had a history of exhibiting behaviour that posed a risk to self by length of admission.

Figure 77:
Number of Patients with Risk to Self by Time Bandings

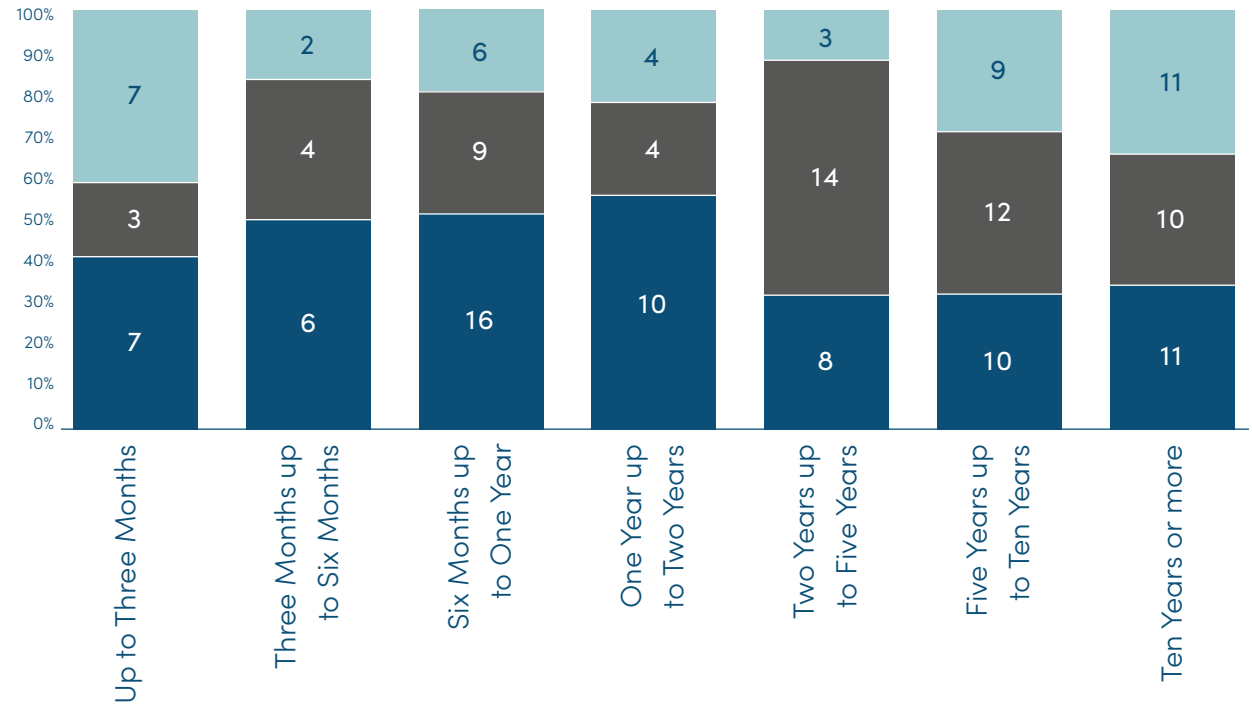
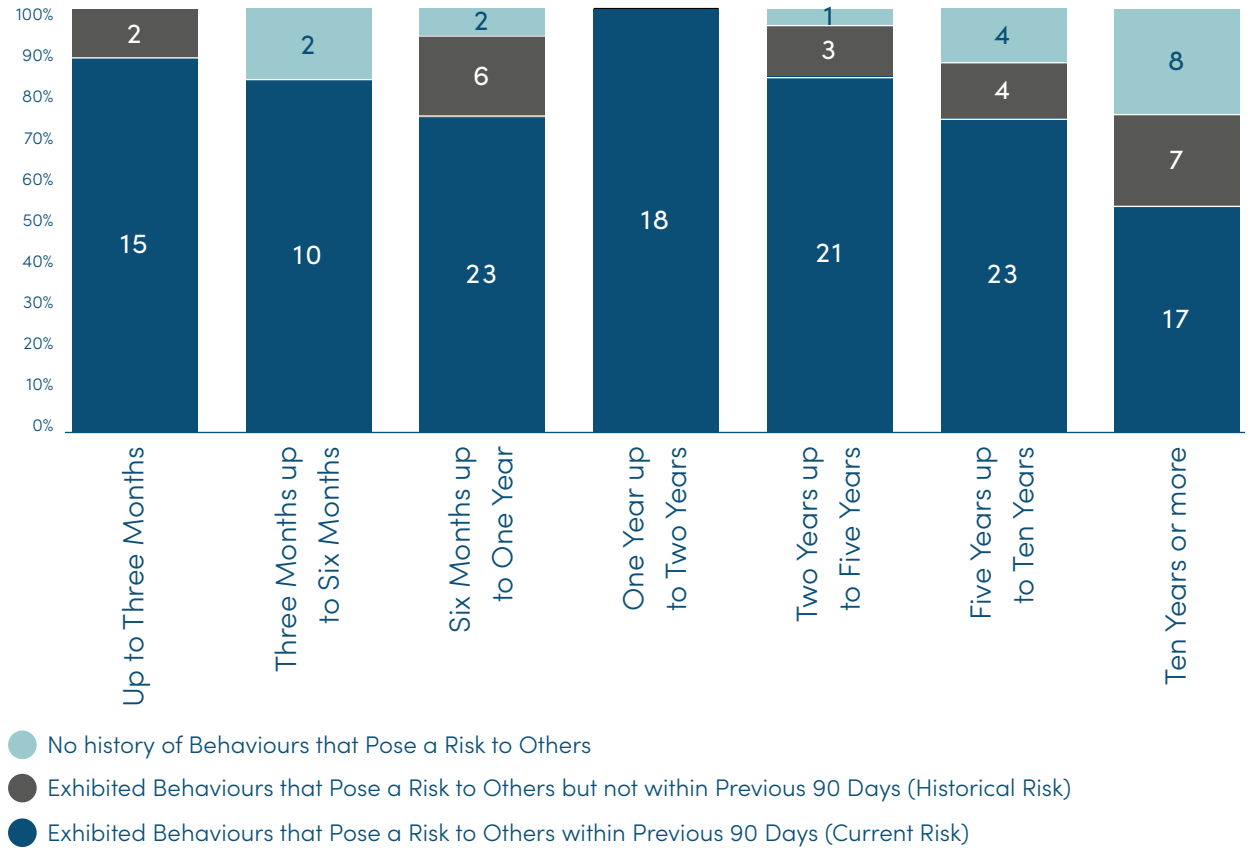


Figure 78 presents the number of patients who had a history of exhibiting behaviours that pose a risk to others by length of admission.

Figure 78:

Number of Patients with Risk to Others by Time Bandings



Both Figure 77 and 78 indicate that patients with the longest lengths of stay were the least likely to exhibit current risk. As soon as risks have reduced, or would likely be reduced by moving to a community setting, consideration should be given to transition even if this means that assessment and treatment continues in the community.[138]

National Care Review Recommendations

30) **Providers should record all incidents of behaviours that challenge.**
31) **Providers should deliver a safe, effective and therapeutic environment of care in order to reduce frustration and boredom which could lead to behaviours that challenge.**
32) **Providers should ensure that staff are trained to recognise escalating behaviours and to deliver positive and preventative interventions.**
33) **Commissioners should ensure that providers are taking considered positive risks and are not focusing exclusively on historical risk.**
34) **Providers must ensure that staff well-being is protected if they are regularly exposed to behaviours that challenge.**

21. Restrictive Interventions

Restrictive interventions can be defined as planned or reactive acts that limit an individual's movement, liberty or freedom to act independently, in order to take immediate control of a situation where there is a real possibility of harm to the individual or others.[139] Restrictive interventions can include such activities as seclusion, physical restraint or chemical restraint.

Restrictive interventions should only be used when all other strategies have been tried and found to be unsuccessful or, in an emergency, when the risks of not employing a restrictive intervention are greater than the risks of using them.[140] Some restrictive interventions, such as restraint and seclusion, can be potentially dangerous and have led to fatalities in the United Kingdom.[141]

Restrictive interventions should always seek to achieve a resolution that reflects the best interests of the individual whose behaviour is of immediate concern and of any others who might be affected by such behaviour. Whether used on a planned or emergency basis, restrictive interventions should only be used to prevent injury, avert serious damage to property or to enable appropriate delivery of essential care in a dignified manner.[142] Restrictive interventions should involve the minimum degree of force, for the briefest amount of time and with due consideration for the self-respect, dignity, privacy, cultural values and individual needs of the patient.

This National Care Review looked at the following six restrictive interventions:

- Staff have used physical interventions such as hands-on guidance but not restraint.
- Staff manage the patient's risk through facilitating 'time out' in a bedroom or quiet room.
- Staff have restrained the patient, but not on the floor.
- Staff have restrained the patient on the floor, but the patient is not 'face down'.
- Staff have secluded (isolated) the patient.
- Staff have restrained the patient 'face down' on the floor.

This National Care Review found that 120 patients (72%), of whom 83 were male and 37 were female, had been subject to one or more restrictive interventions. 60 patients (36%) had been subject to one or more restrictive interventions at least once in the previous ninety days.

36%

Patients subject to

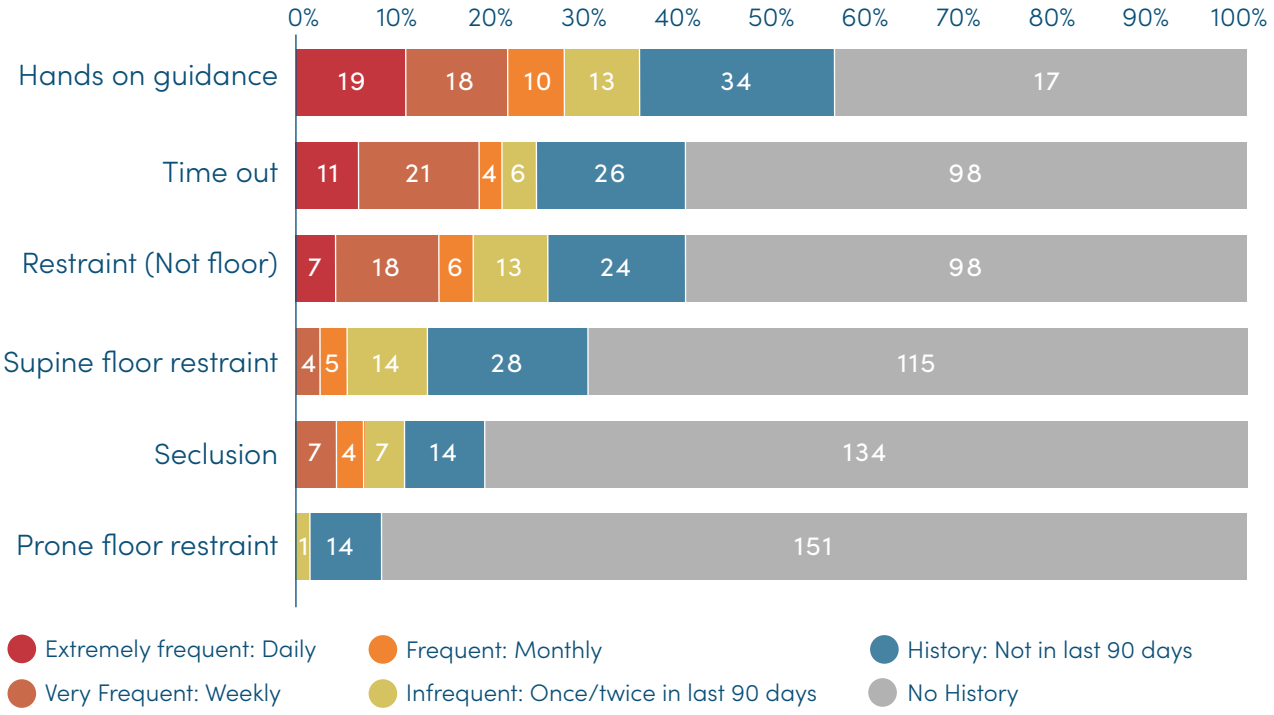
ONE OR MORE RESTRICTIVE INTERVENTIONS

within the previous ninety days

Figure 79 presents the number of patients subject to each of the six restrictive interventions, and shows that 'hands on guidance' was the intervention most frequently used, with 94 patients (57%) subject to it.

Figure 79:

Frequency of Restrictive Interventions



This National Care Review found that the following proportion of patients in each type of provider had been subject to one or more restrictive interventions:

- 100% of patients of patients in medium secure units.
- 82% of patients in low secure units.
- 83% of patients in controlled egress units.
- 80% of patients in uncontrolled egress units.
- 57% of patients in continuing care units.

Figure 80 presents the number of patients subject to one or more restrictive interventions, by type of provider.

Figure 80:

Percentage of Patient Subject to One or More Restrictive Interventions by Type of Provider, Frequency & Gender

	Medium Secure	Low Secure	Controlled Egress	Assessment & Treatment	Uncontrolled Egress	Continuing Care	Low Secure	Controlled Egress	Assessment & Treatment	Continuing Care
	Male Patients						Female Patients			
No History		22%	20%	23%	20%	41%		14%	38%	48%
History: Not in Last 90 Days	13%	26%		15%	60%	18%		21%	13%	8%
Infrequent: Once/Twice in Last 90 Days	38%	26%	25%	8%		4%	20%	14%	13%	4%
Frequent: Monthly		9%	5%			6%	20%	21%	13%	
Very Frequent: Weekly	38%	13%	25%	31%		18%	20%	21%	13%	16%
Extremely Frequent: Daily	13%	4%	25%	23%	20%	12%	40%	7%	13%	24%

21.1 Hands-On Guidance

Restrictive Intervention: Staff have used a physical intervention with the patient, such as guiding them out of harms way, but have not restrained the patient.

This restrictive intervention involves those instances where staff are directing the actions of a patient or stopping them from carrying out a particular action by using 'hands-on guidance'. It is important for this intervention to be recorded, in order to detect misuse or overuse and to prevent misunderstanding between hands-on guidance and restraint.

This National Care Review found that 94 patients (57%) had been subject to hands-on guidance, of whom 64 were male and 30 were female. Figure 81 presents the number of patients subject to hands-on guidance, by type of provider.

Figure 81:

Number of Patients Subject to Hands-on Guidance by Type of Provider, Frequency & Gender

	Male Patients						Female Patients			
	Medium Secure	Low Secure	Controlled Egress	Assessment & Treatment	Uncontrolled Egress	Continuing Care	Low Secure	Controlled Egress	Assessment & Treatment	Continuing Care
No History	2	12	4	5	1	26	1	5	5	11
History: Not in Last 90 Days	3	4	3	2	3	9	1	4		5
Infrequent: Once/Twice in Last 90 Days	2	2	2	1		3	1	1		1
Frequent: Monthly		2	2			3	1	1	1	
Very Frequent: Weekly		3	2	2		4		2	1	4
Extremely Frequent: Daily	1		3	3	1	4	1	1	1	4

Data from NHS England shows that 6% of patients had been subject to a 'restrictive escort' within one month[143] compared to 28% in Wales, although definitions may differ.

Figure 82 presents the number of patients who had been subject to hands-on guidance, and shows that female patients had been subject to this type of restrictive intervention more frequently than males.

Figure 82:
Number of Patients Subject to Hands-on Guidance by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	50 (44%)	24 (21%)	10 (9%)	7 (6%)	11 (10%)	12 (11%)
Female	22 (42%)	10 (19%)	3 (6%)	3 (6%)	7 (13%)	7 (13%)

21.2 Time Out

Restrictive Intervention: **Staff manage the patient's risk through isolating them from other patients, but not staff, in a bedroom or quiet room.**

This restrictive intervention removes the patient from an activity, circumstance or environment that may be exacerbating the behaviour that challenges.[144]

This National Care Review found that 68 patients (41%) been subject to time out, of whom 52 were male and 16 were female. Figure 83 presents the number of patients subject to time out, by type of provider.

Figure 83:

Number of Patients Subject to Time Out by Type of Provider, Frequency & Gender

	Male Patients						Female Patients			
	Medium Secure	Low Secure	Controlled Egress	Assessment & Treatment	Uncontrolled Egress	Continuing Care	Low Secure	Controlled Egress	Assessment & Treatment	Continuing Care
No History	4	14	6	6	3	29	1	12	5	18
History: Not in Last 90 Days	1	4	2	3	2	9	1	1		3
Infrequent: Once/Twice in Last 90 Days	1	1	2	1		1				
Frequent: Monthly		1	1			1			1	
Very Frequent: Weekly	1	2	4	3		6	1	1	1	2
Extremely Frequent: Daily	1	1	1			3	2		1	2

Figure 84 presents the number of patients that had been subject to time out, by gender, and shows that male patients had been subject to this type of restrictive intervention more frequently than female patients.

Figure 84:

Number of Patients Subject to Time Out by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	62 (54%)	21 (18%)	6 (5%)	3 (3%)	16 (14%)	6 (5%)
Female	36 (69%)	5 (10%)	0 (0%)	1 (2%)	5 (10%)	5 (10%)

21.3 Restraint, Not Floor

Restrictive Intervention: Staff manage the patient's risk by a taught, hands-on method of physical restraint whilst the patient is either standing, sitting or kneeling.

Restraint should be used by staff to prevent patients from harming themselves, endangering others or compromising the therapeutic environment. Its purpose is to safely immobilise the patient.[145]

This National Care Review found that 78 patients (48%) had been subject to restraint, not floor, of whom 51 were male and 27 were female. Figure 85 presents the number of patients subject to restraint, not floor, by type of provider.

Figure 85:

Number of Patients Subject to Restraint (not Floor) by Type of Provider, Frequency & Gender

	Male Patients						Female Patients			
	Medium Secure	Low Secure	Controlled Egress	Assessment & Treatment	Uncontrolled Egress	Continuing Care	Low Secure	Controlled Egress	Assessment & Treatment	Continuing Care
No History	1	11	7	8	1	35	1	1	5	18
History: Not in Last 90 Days	5	5	3	1	4	8		5	1	1
Infrequent: Once/Twice in Last 90 Days	1	4	1	2		1	2	4	1	4
Frequent: Monthly		2	2			1	1	2		1
Very Frequent: Weekly		1	3	1		3		2	1	1
Extremely Frequent: Daily	1			1		1	1			

Figure 86 presents the number of patients subject to restraint, not floor, by gender, and shows that male patients had been subject to this type of restrictive intervention more frequently than female patients.

Figure 86:
Number of Patients Subject to Restraint (not Floor) by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	63 (55%)	26 (23%)	9 (8%)	5 (4%)	8 (7%)	3 (3%)
Female	25 (48%)	7 (13%)	11 (21%)	4 (8%)	4 (8%)	1 (2%)

21.4 Supine Restraint

Restrictive Intervention: **Staff manage the patient's risk by a hands-on method of physical restraint with the patient on their back, normally on the floor or a bed.**

Studies promote the alternative of restraining the patient in a chair or on a bed rather than on the floor.[146]

This National Care Review found that 51 patients (31%) had been subject to supine restraint, of whom 36 were male and 15 were female. Figure 87 presents the number of patients subject to supine restraint, by type of provider.

Figure 87:

Number of Patients Subject to Supine Restraint by Type of Provider, Frequency & Gender

	Male Patients						Female Patients			
	Medium Secure	Low Secure	Controlled Egress	Assessment & Treatment	Uncontrolled Egress	Continuing Care	Low Secure	Controlled Egress	Assessment & Treatment	Continuing Care
No History	4	16	5	9	2	42	1	8	7	21
History: Not in Last 90 Days	3	4	4	2	3	6	1	3		2
Infrequent: Once/Twice in Last 90 Days	1	1	5			1		3	1	2
Frequent: Monthly		1	1	1			2			
Very Frequent: Weekly		1	1	1			1			
Extremely Frequent: Daily										

Figure 88 presents the number of patients who had been subject to supine restraint, by gender, and shows that male patients had been subject to this type of restrictive intervention more frequently than female patients.

Figure 88:

Number of Patients Subject to Supine Restraint by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	78 (68%)	22 (19%)	8 (7%)	3 (3%)	3 (3%)	0 (0%)
Female	37 (71%)	6 (12%)	6 (12%)	2 (4%)	1 (2%)	0 (0%)

21.5 Seclusion

Restrictive Intervention: Staff manage the patient's risk by isolating the patient away from others, in an area from which the patient is subsequently prevented from leaving.

This National Care Review found that 32 patients (19%) had been subject to seclusion, of whom 28 were male and 4 were female.

Figure 89 presents the number of patients subject to seclusion, by type of provider.

Figure 89:

Number of Patients Subject to Seclusion by Type of Provider, Frequency & Gender

	Male Patients						Female Patients			
	Medium Secure	Low Secure	Controlled Egress	Assessment & Treatment	Uncontrolled Egress	Continuing Care	Low Secure	Controlled Egress	Assessment & Treatment	Continuing Care
No History		17	13	11	5	40	3	14	7	24
History: Not in Last 90 Days	4	3	1	1		4				1
Infrequent: Once/Twice in Last 90 Days	2	2	1			1	1			
Frequent: Monthly		1	1			1	1			
Very Frequent: Weekly	2			1		3			1	
Extremely Frequent: Daily										

Studies have stated that no patient with a learning disability '*should ever*' be '*locked in a room on their own*'. However, in some situations, especially where there is a risk of harm to others, it may be an option preferred by both patient and staff. This could be due to the alternative being a long period of restraint with an increased risk of injury, or to the patient having musculoskeletal or respiratory issues which could increase the risk of restraint causing injury.[147]

Figure 90 presents the number of patients who had been secluded, by gender, and shows that male patients had been subject to this type of restrictive intervention more frequently female patients.

Figure 90:
Number of Patients Subject to Seclusion by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	86 (75%)	13 (11%)	6 (5%)	3 (3%)	6 (5%)	0 (0%)
Female	48 (92%)	1 (2%)	1 (2%)	1 (2%)	1 (2%)	0 (0%)

21.6 Prone Restraint

Restrictive Intervention: **Staff manage the patient's risk by a hands-on method of physical restraint with the patient 'face down' on the floor or a bed.**

The use of prone restraint is '*controversial*' due to research that associates this position with an increased risk of death due to positional asphyxia.[148]

This National Care Review found that 15 patients (9%) had been subject to prone restraint, of whom 11 were male and 4 were female, although only one case had been reported in the previous ninety days.

Figure 91 presents the number of patients subject to prone restraint, by type of provider.

Figure 91:

Number of Patients Subject to Prone Restraint by Type of Provider, Frequency & Gender

	Medium Secure	Low Secure	Controlled Egress	Assessment & Treatment	Uncontrolled Egress	Continuing Care	Low Secure	Controlled Egress	Assessment & Treatment	Continuing Care
	Male Patients						Female Patients			
No History	7	21	15	12	2	46	4	12	8	24
History: Not in Last 90 Days	1	1	1	1	3	3	1	2		1
Infrequent: Once/Twice in Last 90 Days		1								
Frequent: Monthly										
Very Frequent: Weekly										
Extremely Frequent: Daily										

The Mental Health Act Code of Practice for Wales (Revised 2016) states that prone restraint is only to be used in '*exceptional circumstances*' and where is it essential to maintain the safety of the patient and others.[149]

Figure 92 presents the number of patients subject to prone restraint, by gender, and shows that male patients had been subject to this type of restrictive intervention more frequently than female patients.

Figure 92:

Number of Patients Subject to Prone Restraint by Frequency & Gender

	No History	History: Not in Last 90 Days	Infrequent: Once/Twice in Last 90 Days	Frequent: Monthly	Very Frequent: Weekly	Extremely Frequent: Daily
Male	103 (90%)	10 (9%)	1 (1%)	0 (0%)	0 (0%)	0 (0%)
Female	48 (92%)	4 (8%)	0 (0%)	0 (0%)	0 (0%)	0 (0%)

National Care Review Recommendation

35) Providers should ensure that any restrictive intervention involves the minimum degree of force, for the briefest amount of time and with due consideration of the self-respect, dignity, privacy, cultural values and individual needs of the patient.

22. Reducing Restrictive Interventions

Restrictive interventions can be used when they are part of a hospital support plan and when there is no other way to keep the patient safe. In these situations, staff must ensure that the care, treatment and support they provide is safe, effective, person-centred and provided within legal, ethical and professional accountability structures.[150]

In Wales, the Mental Health Act Code of Practice (Revised 2016) states that hospital managers should ensure the Health Board receives regular reports from each unit about '*violent incidents*', the use of restrictive interventions, and the patients' experience of those interventions.[151]

It is Welsh Government policy to reduce the inappropriate use of restrictive interventions for individuals with a learning disability through prevention, early intervention and increasing the use of approaches such as 'Positive Behavioural Support' and 'Active Support'.[152]

Although there is no approach that will eliminate restrictive interventions, there are actions, such as improving the ward environment, unit milieu and staff training, which can support reduction. Other actions which can support a reduction in restrictive interventions include involving patients in changing the unit's culture and supporting patients to manage their own distress.[153]

Value and Types of Provider

Each average value is determined separately for each type of provider. Typically, different types of provider have different levels of environmental, relational and procedure security that minimise or prevent behaviours that challenge. The establishment, skills, experience and expectations of staff may also differ between types of provider.

Studies have shown that caring for patients in the right environment reduces behaviour which challenges' and that patients exhibiting such behaviours benefit from '*personalised care*'.[154]

New training standards for restrictive interventions will improve the quality of training provided to staff as well as focusing on supporting staff to understand and meet the needs of the patients in distress.[155]

This National Care Review used a bespoke method to apply a numerical value to each of the types of behaviours that challenge, each different restrictive intervention and the psychotropic medications prescribed. These measures are based on the intensity and frequency of the behaviour, intervention or prescription on a custom-built scale [see box]. These measures enable benchmarking and highlighting of good practice or practice of concern.

Figure 93 presents the average value of the behaviours that challenge measure, the restrictive intervention measure and the psychotropic medications measure, for male and female patients cared for in each type of provider.

Figure 93:

Average 'value' of behaviours that challenge measure (reportable range 0-75), restrictive intervention measure (reportable range 0-59) and psychotropic medications measure (reportable range 0-12), by type of provider and gender. Colour coding distinct to each measure.

	Medium Secure	Low Secure		Controlled Egress		Assessment & Treatment		Uncontrolled Egress	Continuing Care	
	Male	Male	Female	Male	Female	Male	Female	Male	Male	Female
Challenging Behaviour Measure	27	18	36	21	27	35	19	18	21	18
Restrictive Intervention Measure	22	11	30	18	12	13	11	11	8	7
Psychotropic Medication Measure	4	4	5	5	6	6	6	6	4	4

Considering the information for all patients as an average value across each provider can screen individual differences. Figure 94 presents the 28 patients cared for in low secure units and the 'value' of their individual challenging behaviour measure, restrictive intervention measure and psychotropic medication measure.

Only one type of provider has been shown in the main body of this National Care Review for space-saving purposes, and information for all other types of provider can be found in **Appendix B**.

Figure 94:

Triangulation of value of behaviours that challenge measure (reportable range 0-75), restrictive intervention measure (reportable range 0-59) and psychotropic medications measure (reportable range 0-12) for all patients being cared for in low secure units. Colour coding distinct to each measure. Listed by challenging behaviour measure value

Patient	Gender	Challenging Behaviour Measure	Restrictive Intervention Measure	Psychotropic Medication Measure
1	Male	58	10	8
2	Male	37	33	11
3	Male	30	12	6
4	Male	28	8	6
5	Male	26	59	6
6	Male	25	18	5
7	Male	22	10	3
8	Male	18	0	1
9	Male	17	8	3
10	Male	17	3	0
11	Male	15	6	0
12	Male	15	18	6
13	Male	14	13	3
14	Male	12	2	4
15	Male	12	20	7
16	Male	12	13	8
17	Male	12	6	3
18	Male	10	0	2
19	Male	9	0	1
20	Male	8	2	0
21	Male	6	18	7
22	Male	4	0	0
23	Male	1	0	6
24	Female	55	46	6
25	Female	41	31	7
26	Female	37	35	6
27	Female	31	31	6
28	Female	18	9	1

The values across the three measures shown in Figure 94 indicate possible individual patterns that should be examined further. For example:

- Patients 'two' and 'twenty-four' exhibited frequent/intensive behaviours that challenge that required frequent restrictive interventions and a complex psychotropic medication regime.
- Patient 'five', who was subject to the most frequent/intensive restrictive interventions and a relatively complex medication regime, did not exhibit the most intense/frequent behaviours that challenge.
- Patient 'twenty-three' did not exhibit frequent/intensive behaviours that challenge or require restrictive interventions, but had a complex psychotropic medication regime which could indicate 'chemical restraint'.

National Care Review Recommendations

36) Providers should ensure that all incidents of restrictive interventions are recorded, reviewed and reported.
37) Providers should ensure that any restrictive intervention is proportionate to the risk posed by the behaviour that challenges.
38) Commissioners should ensure that all providers of restrictive intervention training comply with the 2019 Restraint Reduction Network Training Standards.
39) Commissioners should ensure that providers have a restraint reduction plan in place for each patient.

23. Personal & Blanket Restrictions

Within hospital environments, it is sometimes necessary to restrict access to areas or items in order to prevent harm to the individual or others. Restrictions must always be proportionate to the harm which staff are seeking to prevent. This National Care Review divided personal restrictions into the following seven categories:

- Restricted access to bedrooms during particular times, normally daytime or activity periods.
- Restricted access to other areas of service, for example drink-making areas, during particular times such as night-time.
- Restricted access to outdoor space such as garden areas.
- Restricted access to own finances.
- Restricted access to communication devices such as mobile phones.
- Subject to visitor restrictions.
- Restricted access to risk items such as razors and deodorants.

This National Care Review looked at the application of each of these personal restrictions, and found that 128 patients (77%) were subject to at least one personal restriction.

77%
Patients were subject to one to at least one
PERSONAL RESTRICTION

In hospitals, personal restrictions can form part of the broader package of environmental, procedural and relational security measures. Figure 95 presents the number of patients subject to at least one personal restriction, by type of provider.

Figure 95:
Number of Patients Subject to One or More Personal Restriction

	Patients Subject to at Least One Personal Restriction
Medium Secure	5 (63%)
Low Secure	26 (93%)
Controlled Egress	21 (70%)
Assessment & Treatment	19 (90%)
Uncontrolled Egress	4 (80%)
Continuing Care	53 (72%)

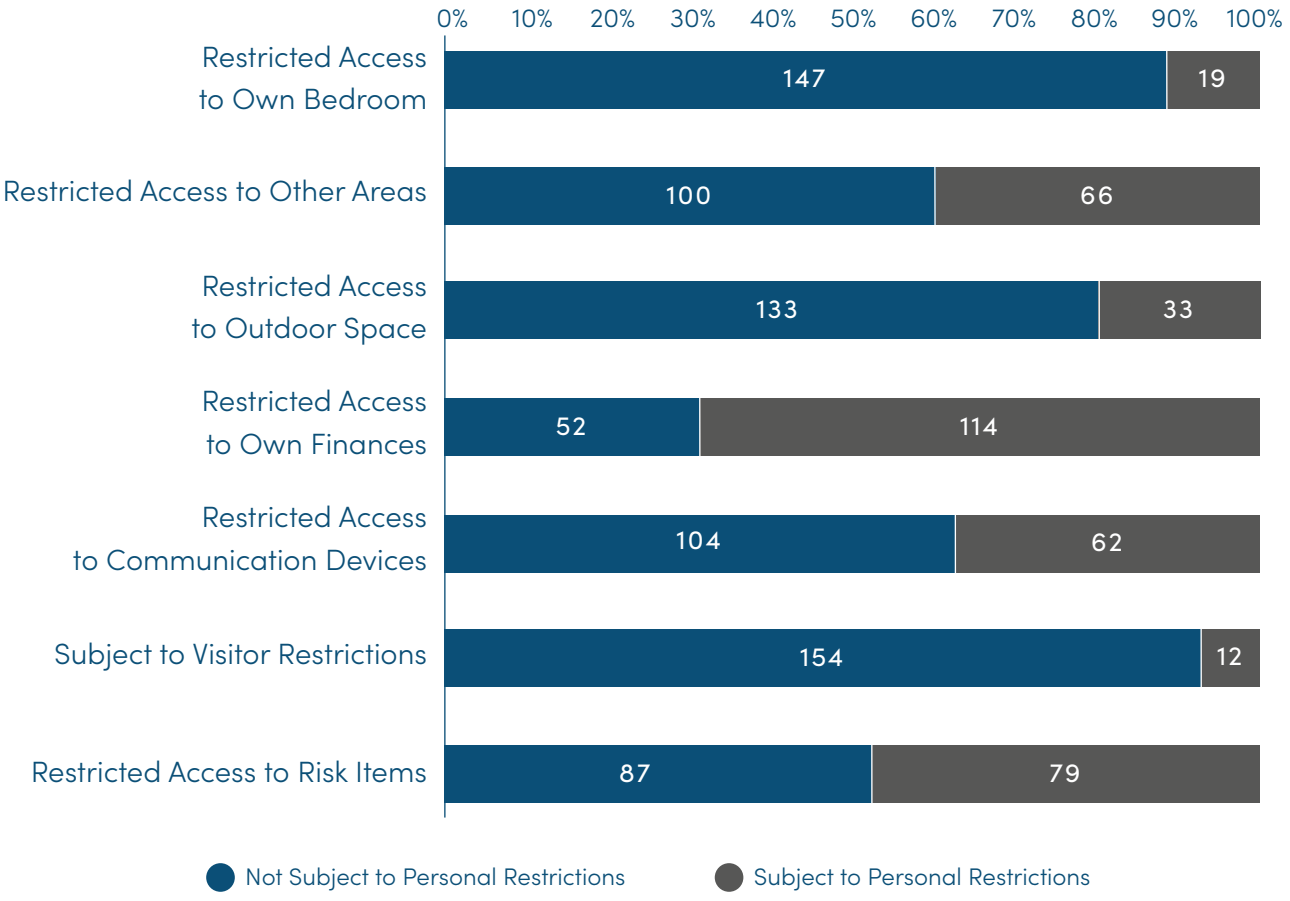
The application of personal restrictions should be avoided unless justified as a necessary and proportionate response to the risks identified for particular individuals. The impact of a restriction should be considered and documented in the patient's hospital support plan. Personal

restrictions should never be applied in order to punish or humiliate, only as a measured response for the shortest period.

Figure 96 presents the number of patients subject to each of the seven categories of personal restrictions, and shows that restricting access to own finances was applied to the highest number of patients (114, or 69%) and visitor restrictions was applied to the lowest number of patients (12, or 7%).

Figure 96:

Number of Patients Subject to a Specific Personal Restriction



Some restrictions are applied not just to a single patient but routinely to all patients, without individual risk assessments to justify their application. These are usually termed 'blanket' restrictions. The Mental Health Act Code of Practice allows for the use of 'blanket' restrictions only in specific circumstances, and states that they should never be used for the '*convenience of the provider*'.[156]

Additional restrictions such as dietary restrictions, restricted access to personal items, activities and opportunities, or any other practice where staff are able to impose conditions on patients, should be viewed as restrictive interventions and therefore reviewed regularly to prevent them from becoming '*coercive and/or physically, emotionally or psychologically harmful*'.[157]

National Care Review Recommendations

40) **Providers should ensure that the rationale for application, and planned duration, for any and all personal restrictions should be clearly documented in the patient's hospital support plan and be regularly reviewed.**

41) **Commissioners should ensure that all blanket restrictions are proportionate, have a clear rationale for application and are subject to regular review.**

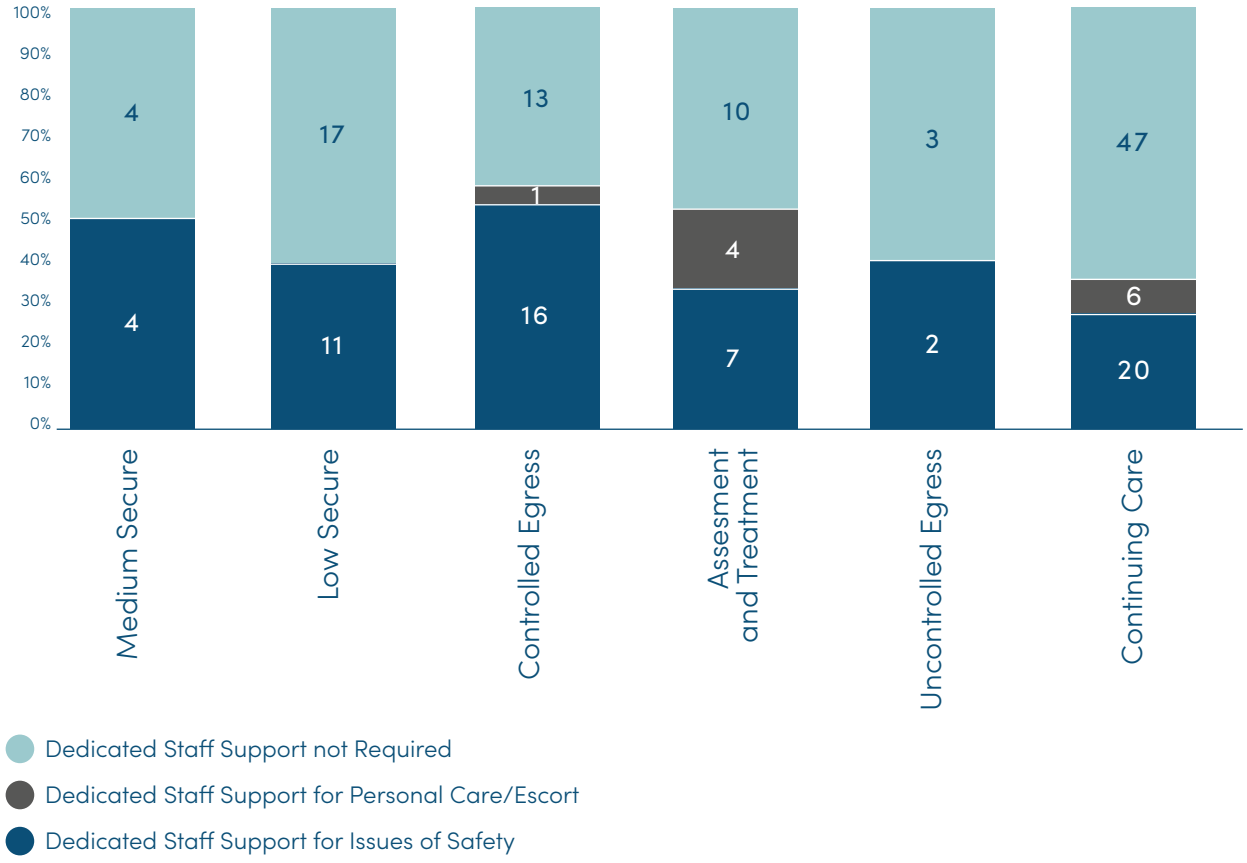
24. Dedicated Staff Support

Some patients require dedicated staff support to wash and dress, to attend activities, to accompany them outside the hospital, or to stay with them whilst in hospital to ensure their safety or the safety of others. These arrangements are called 'patient observations', 'escorts' or 'one-to-one care'.

This National Care Review found that overall 71 patients (43%) were receiving dedicated staff support.

Figure 97 presents the number of patients who were receiving dedicated staff support, by type of provider. It shows that 60 patients (37%) had dedicated staff support to maintain their safety/ the safety of others, and an additional 11 patients (7%) had dedicated staff support to address personal care issues/activities.

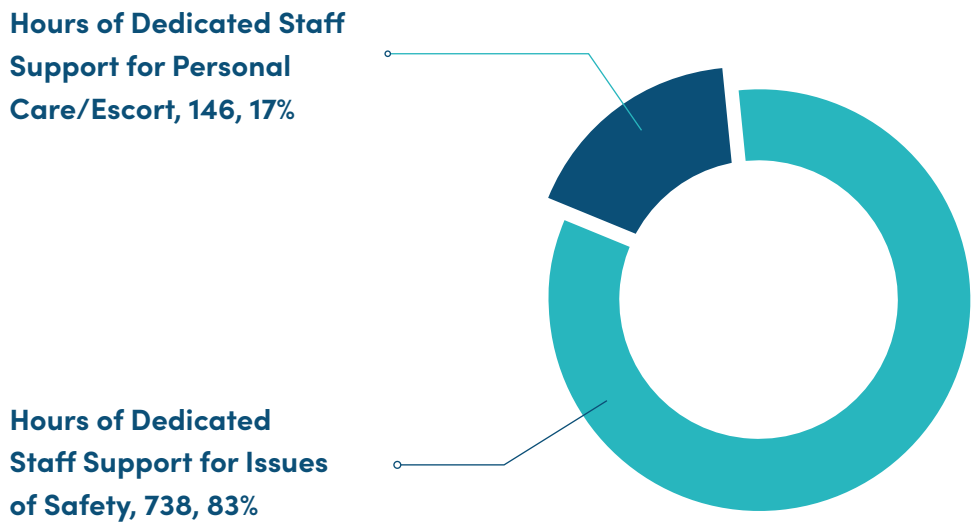
Figure 97:
Number of Patients Receiving Dedicated Staff Support, by Type of Provider



This National Care Review found that a total of 884 dedicated hours were being provided to patients per day. Figure 98 presents the total number of dedicated hours provided per day for issues of safety or to support personal care/undertake escorts.

Figure 98:

Number of Hours of Dedicated Staff Support Provided Per Day



Any clear delineation between the two reasons for the provision of dedicated support is artificial, as there is overlap as staff maintain a patient's safety whilst addressing personal care issues or undertaking escorts and vice versa.

The National Care Review found that, on average, a patient receiving dedicated support did so for 10 hours a day. When provided, dedicated support ranged from thirty minutes to twenty-four hours per day.

Studies have found that providing '*high levels*' of dedicated support, or providing it for long periods, can lead to feelings of '*isolation*' and '*dehumanisation*'.[158]

884
TOTAL AMOUNT OF DEDICATED HOURS
being provided per day

There is an expectation that all providers will offer dedicated support to a patient, if necessary, in a manner that is unobtrusive, safe, supportive and for the minimum period necessary.[159]

National Care Review Recommendation

42) Providers should ensure that any dedicated support balances the risk to a patient's safety with the promotion of dignity and independence.

25. Community Access

Providers should be preparing patients for successful return to greater independence, and periods of overnight leave or community access can form an essential component of that preparation.

Any decision to agree a period of community access has to balance the contribution that this makes to the individual's recovery against considerations for the health and well-being of both the individual and others. For patients detained under the Mental Health Act it is a requirement for 'leave' to be authorised, and certain Sections require authorisation from the Ministry of Justice. Individuals subject to a Deprivation of Liberty may have documented conditions for accessing the community.

As the patient progresses through their personal care journey, community access may progress from being escorted by staff into the local area, to having unescorted leave, to going on overnight leave to home or another care facility as part of transition.

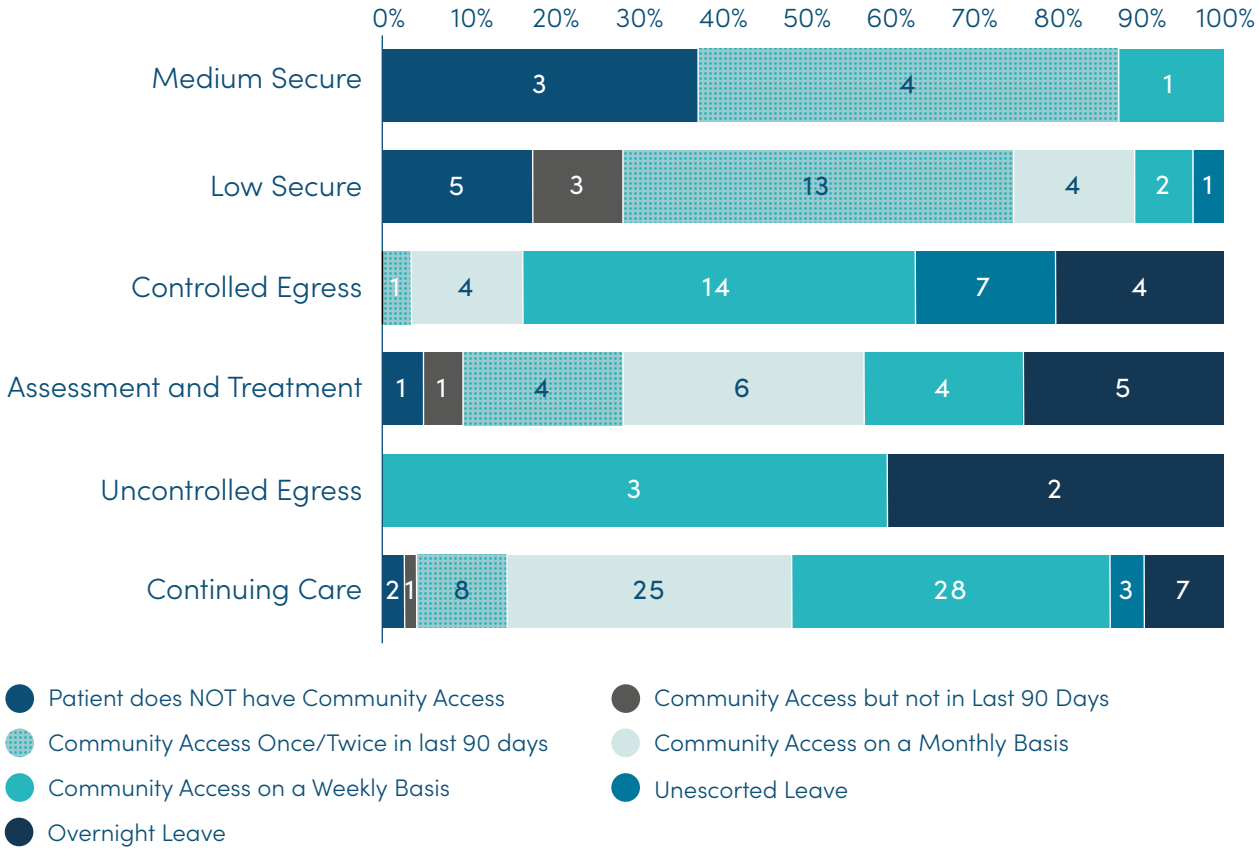
This National Care Review looked at whether, and how often, patients had community access, and found that 153 patients (92%) had some form of community access or overnight leave within the previous ninety days.

92%
Patients with a period
COMMUNITY ACCESS
or
OVERNIGHT LEAVE
Within the previous ninety days

Figure 99 presents the number of patients accessing the community or overnight leave, by frequency and type of provider.

Figure 99:

Number of Patients With Community Access or Overnight Leave by Frequency & Type of Provider



Patients who are accessing the community unescorted could be considered for transition, although many other factors should also be taken into account on determining the appropriate environment of care for a patient.

There is an expectation that all providers of care ensure that community access is planned, taking into consideration risk issues, the patient's best interests and the views of community services and family.[160]

National Care Review Recommendation

43) **Providers should ensure that all patients are enabled and encouraged to access the local community safely.**

26. Physical Health

A major report found that individuals with a learning disability had '*worse health outcomes*' than those of the general population,[161] specifically:

- Greater risk of death from preventable causes.
- Low uptake for national cancer screening.
- Low uptake of immunisations such as influenza vaccinations.
- Reduced access to interventions for obesity, including screening for thyroid disease and diabetes.

These health deficits mean that patients with a learning disabilities experience significantly compromised quality of life.[162] Contributing to this avoidable mortality are the metabolic effects of antipsychotic drug use.[163]

This National Care Review looked at three aspects of physical healthcare: access to primary and preventative health services, access to general healthcare secondary services and access to urgent and emergency health services.

26.1 Access to Primary Care

Individuals with learning disabilities often do not seek out healthcare and when they do, frequently face difficulties.[164]

Patients with a learning disability have the right to access a comprehensive annual health check via their primary care provider, although studies have shown that half of patients miss out on these 'annual GP health checks'.[165] It is Welsh Government policy to improve the take-up and quality of annual health checks.[166]

Patients with a learning disability also had lower rates of cancer screening, most notably in cervical screening for women. [167] It is Welsh Government policy to reduce health inequalities for individuals with a learning disability and to reduce avoidable and premature deaths through early intervention, prevention and accessible health services.[168]

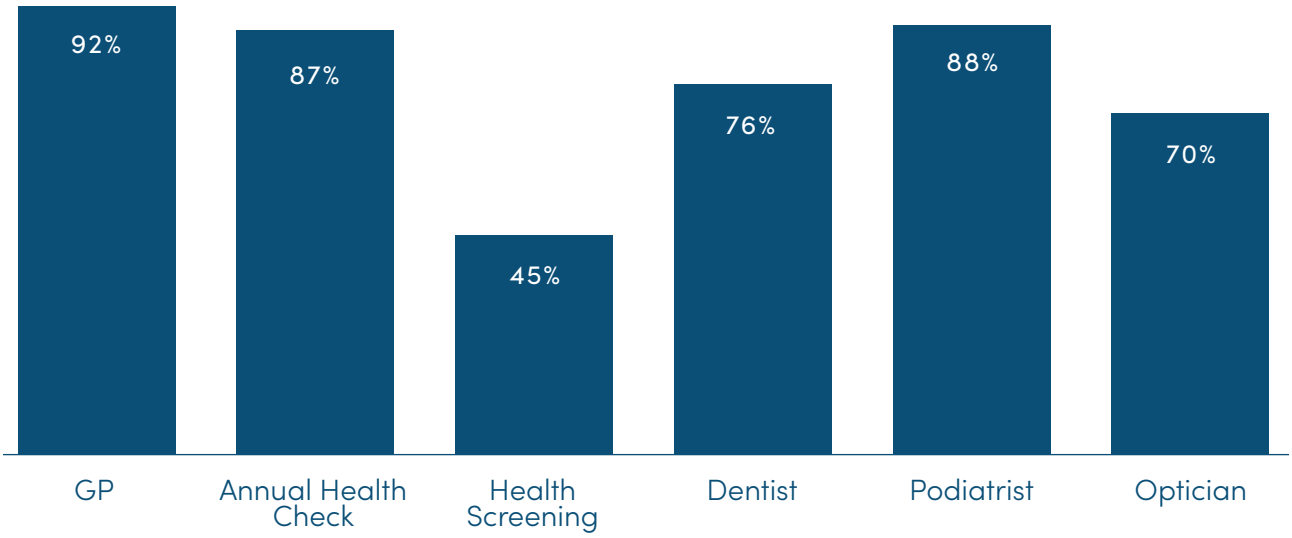
This National Care Review looked at whether patients accessed services such as:

- A GP for check-up/routine appointment.
- A GP for an annual health check.
- Community health screening services, such as breast, cervical, bowel or prostate cancer.
- A dentist for a check-up/routine appointment.
- A podiatrist for check-up/routine appointment.
- An optician for check-up/routine appointment.

This National Care Review had to determine 'eligible patients' for primary care, as some patients may not have been admitted for a long enough period, may have accessed services prior to admission or may be excluded from health screening due to appropriateness.

Figure 100 presents the percentage of eligible patients accessing each primary care service.

Figure 100:
Percentage of Eligible Patients Accessing Primary Care Services



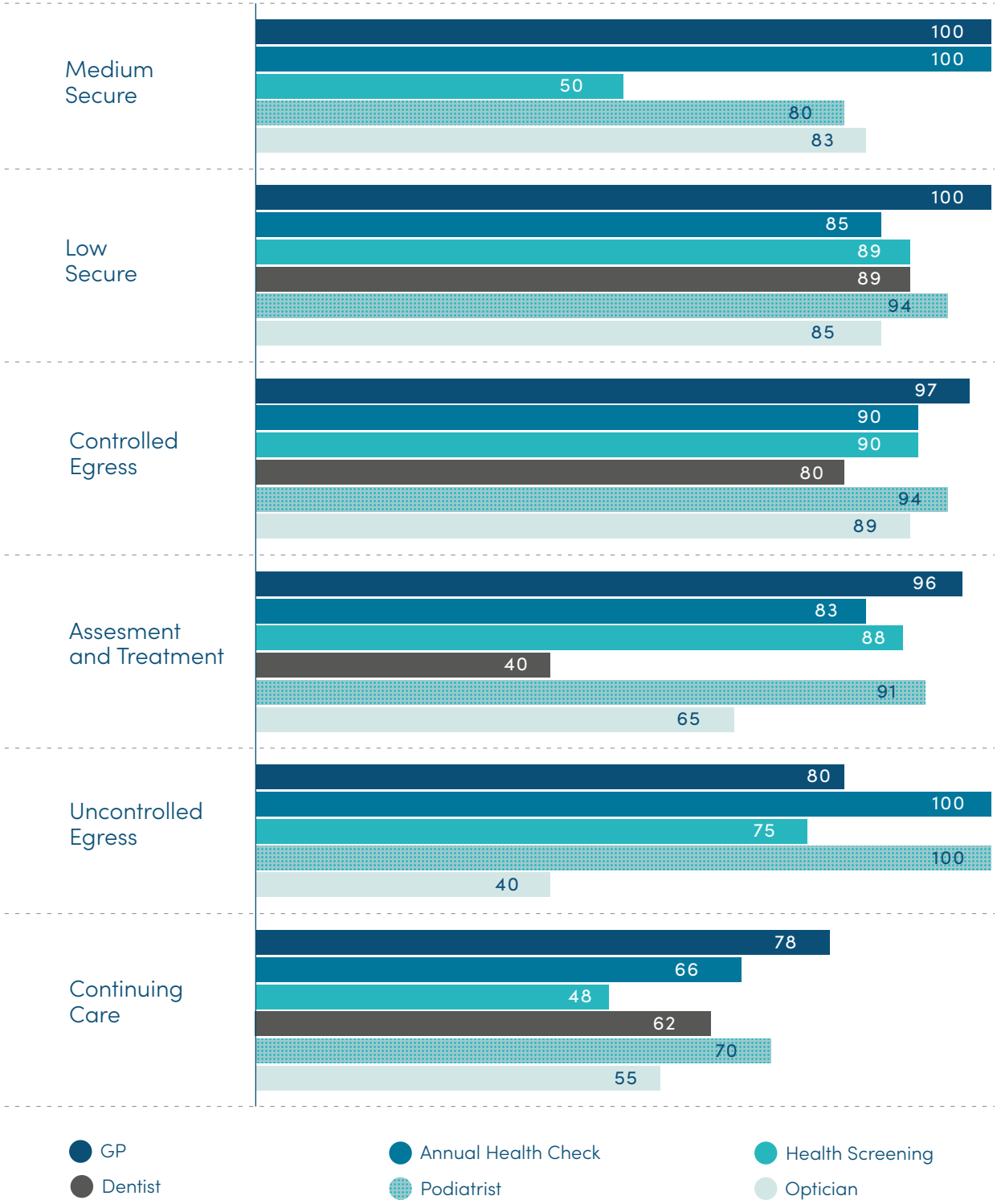
All individuals cared for in independent hospitals receive a GP service, either directly through the provider organisation or from local GP services commissioned by the provider organisation. For the majority of individuals within NHS hospitals, general physical health needs are managed via inpatient medical services, although a small number of patients are registered with local GP services.

Providers should facilitate and enable access to primary care services, ensure that staff plan for patients to attend regular appointments, and be aware of scheduled health checks and health screening appointments.

Figure 101 presents the number of eligible patients accessing specific primary care service within the previous year, by type of provider.

Figure 101:

Percentage of Eligible Patients accessing Primary Care Services, by Type of Provider (0% Health Screening in Medium Secure and Uncontrolled Egress Units)



26.2 Access to Secondary Care

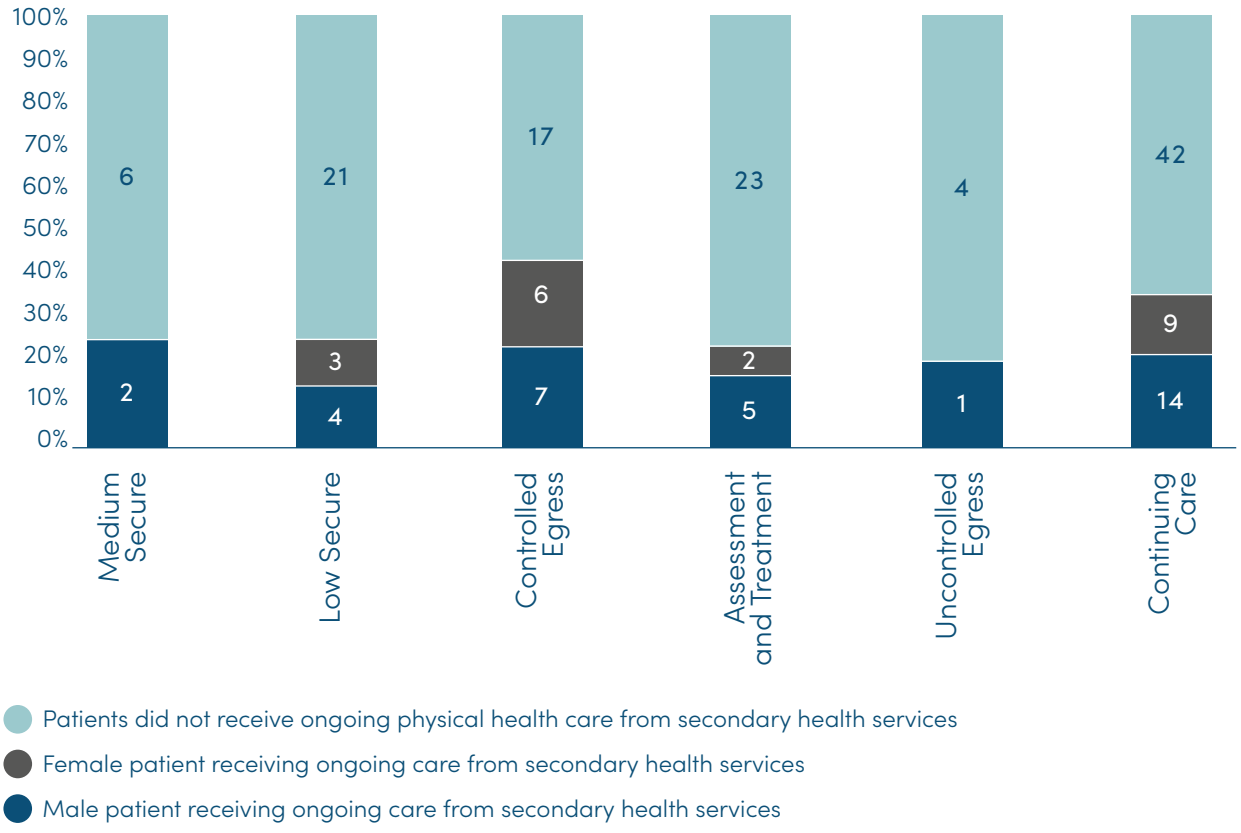
Access to secondary care refers to individuals needing treatment from hospitals, as either an inpatient or an outpatient. Patients with learning disabilities experience a higher prevalence of physical health issues such as epilepsy, constipation or '*swallowing problems*' than the general population.[169]

Some health conditions cause distress which affects the patient's behaviour, particularly where an individual has communication difficulties.[170] Communication difficulties can cause 'diagnostic overshadowing', when a health professional makes an assumption that the behaviour of a patient with learning disabilities is an aspect of their disability rather than a potential symptom of a physical health issue.[171] It is Welsh Government policy to improve secondary care services and tackle diagnostic overshadowing.[172]

This National Care Review looked at whether patients had physical health issues which required ongoing care from secondary care services. Figure 102 presents the number of patients who received ongoing care from secondary health services, and shows that 53 patients (32%) required secondary care in the previous year.

Figure 102:

Number of Patients Who Received Ongoing Care From Secondary Health Services in the Previous Year by Sex & Type of Provider



26.3 Access to Urgent Care

When patients require treatment urgently, they should receive it from skilled, experienced and compassionate staff as quickly as possible.

Studies have highlighted issues for individuals with a learning disability who have come into contact with general healthcare services, around some staff having '*inadequate training and knowledge*' of learning disabilities.[173] A small number of urgent care staff have been found to have '*negative attitudes*' to individuals with a learning disability, although the majority have positive attitudes. [174]

This National Care Review looked at whether patients required urgent care in the previous year, such as:

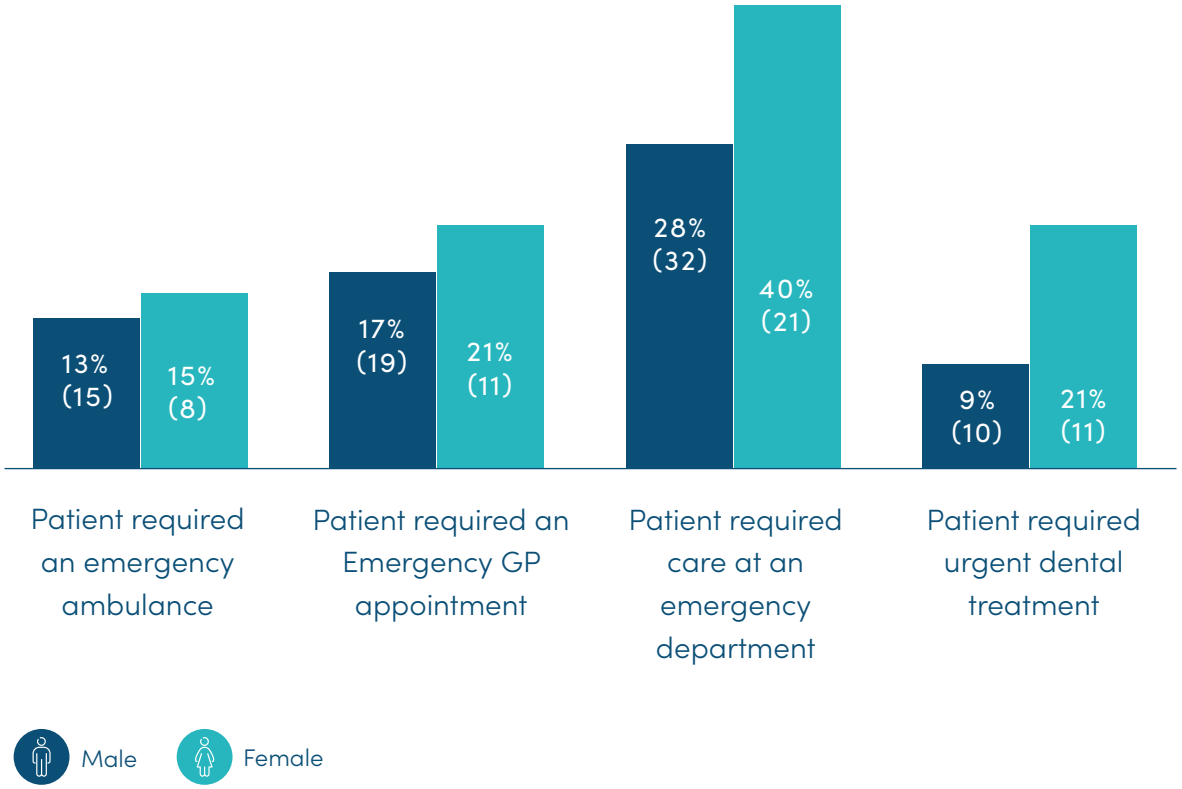
- The patient required urgent dental treatment.
- The patient required assessment by an emergency department.
- The patient required an emergency GP appointment.
- The patient required an emergency ambulance.

This National Care Review found that 33 patients (20%) required one or more urgent care interventions in the previous year, with more female patients (11 or 21%) than male patients (22 or 19%) requiring an intervention.

Figure 103 presents the number of patients requiring urgent care interventions in the previous year, by gender.

Figure 103:

Number of Patients who Received Urgent Care in the Previous Year, by Gender & Intervention



National Care Review Recommendations

44) **Providers should ensure that all patients have access to primary care services as and when required.**

45) **Providers should ensure, where safe to do so, that attendance at urgent care services is prevented by pre-emptive interventions, staffing levels and staff training.**

46) **Commissioners should ensure that general healthcare staff have access to training on learning disabilities and autistic spectrum disorders.**

27. Cost of Care

'Costs' are the monetary value to the NHS of providing a defined service. Costs are made up by totalling the money expended on the building upkeep, patient's food and medication, the pay of clinical, domestic and administration staff, and management overheads. Costs can vary significantly, even for the same type of provider, as elements such as the age and design of buildings, or skills and numbers of staff, can differ.

This National Care Review found that the average cost of one day in hospital for a single patient is £528. Figure 104 presents the costs for one day of care, by type of provider.

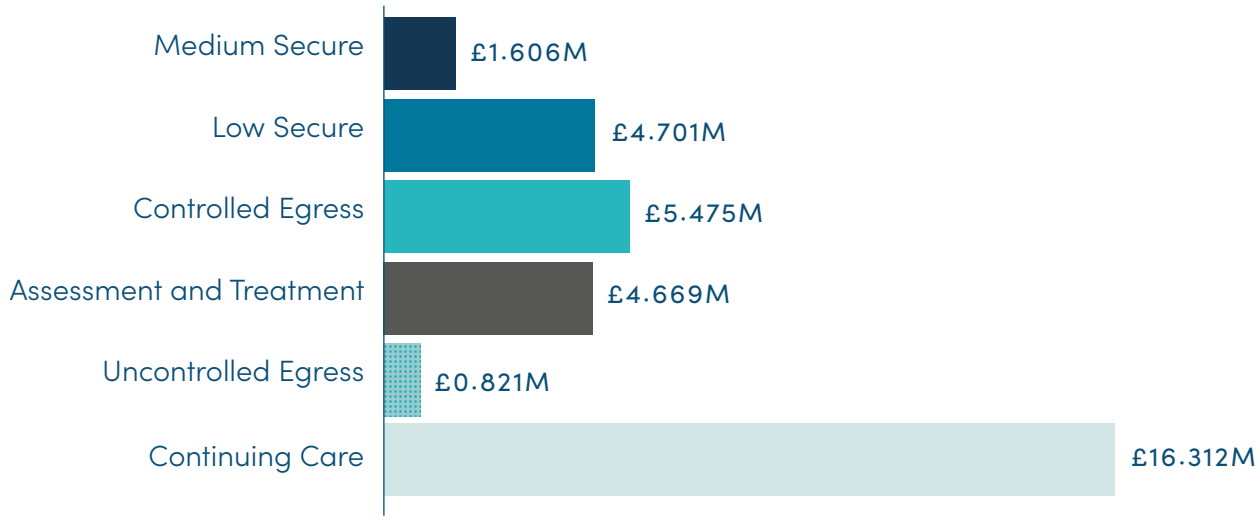
Figure 104:
Cost of One Day of Care by Type of Provider

The total cost of care for a patient is calculated by multiplying the length of admission by the daily cost. Some patients had lengths of stay of several decades, therefore it was not possible to obtain historical costs data in order to determine cost accurately. Due to this constraint, the total cost of care for all patients (based on current cost) is an indicative sum only and amounts to £184,020,331.

This National Care Review found that the annual cost of care***** for all patients was £33.584 million per year. Figure 105 presents the annual costs of care for the patients in a specific type of provider.

Figure 105:

Annual Cost of Care by Type of Provider in £Million



Unit staffing establishments normally include some provision for patients requiring a degree of dedicated support, but this varies widely. If the staffing establishment is inadequate to meet all the dedicated support requirements, additional staff will be required. The provision of these additional members of staff will incur supplementary costs, although some duplication of costs is inevitable as it is unknown how much dedicated support was already included in the staffing establishment. This National Care Review calculated the cost of the 884 dedicated hours discussed in the 'Dedicated Staff Support' section of this National Care Review to be £10,754 per day.

£33.5
MILLION
cost of care per year
for 166 patients

National Care Review Recommendation

47) **Commissioners should ensure that providers deliver best value.**

***** Note: Annual cost of care is cost information based on 2018/19 for a full year placement.

PART C
Patients Voice

'Listening to the experiences of patients, families and carers should be a fundamental way in which services in NHS Wales learn and improve.' [175]

Patient Statements Gathered Through Facilitated Discussions

‘I did something bad’

Patient response when asked why they were admitted to hospital

‘Nothing to do’

Patient response when asked about their care

‘It’s really good, staff are good’

Patient response when asked about their care

‘To get out’

Patient response when asked what was important to them in hospital

‘They listened to me’

Patient response when asked what advocacy had done for them

‘Going home to visit mum’

Patient response when asked what was important to them in hospital

‘Do more things with staff’

Patient response when asked what they would change in hospital

‘It’s Ok but psychology is hard’

Patient response when asked about their care

27.1 Patient Experience & Satisfaction

Patients with a learning disability are the '*experts on their experience of using services*'.[176] The Welsh Government is committed to understanding and improving the patient's experience.[177]

This National Care Review gathered patients' views using the following two methods:

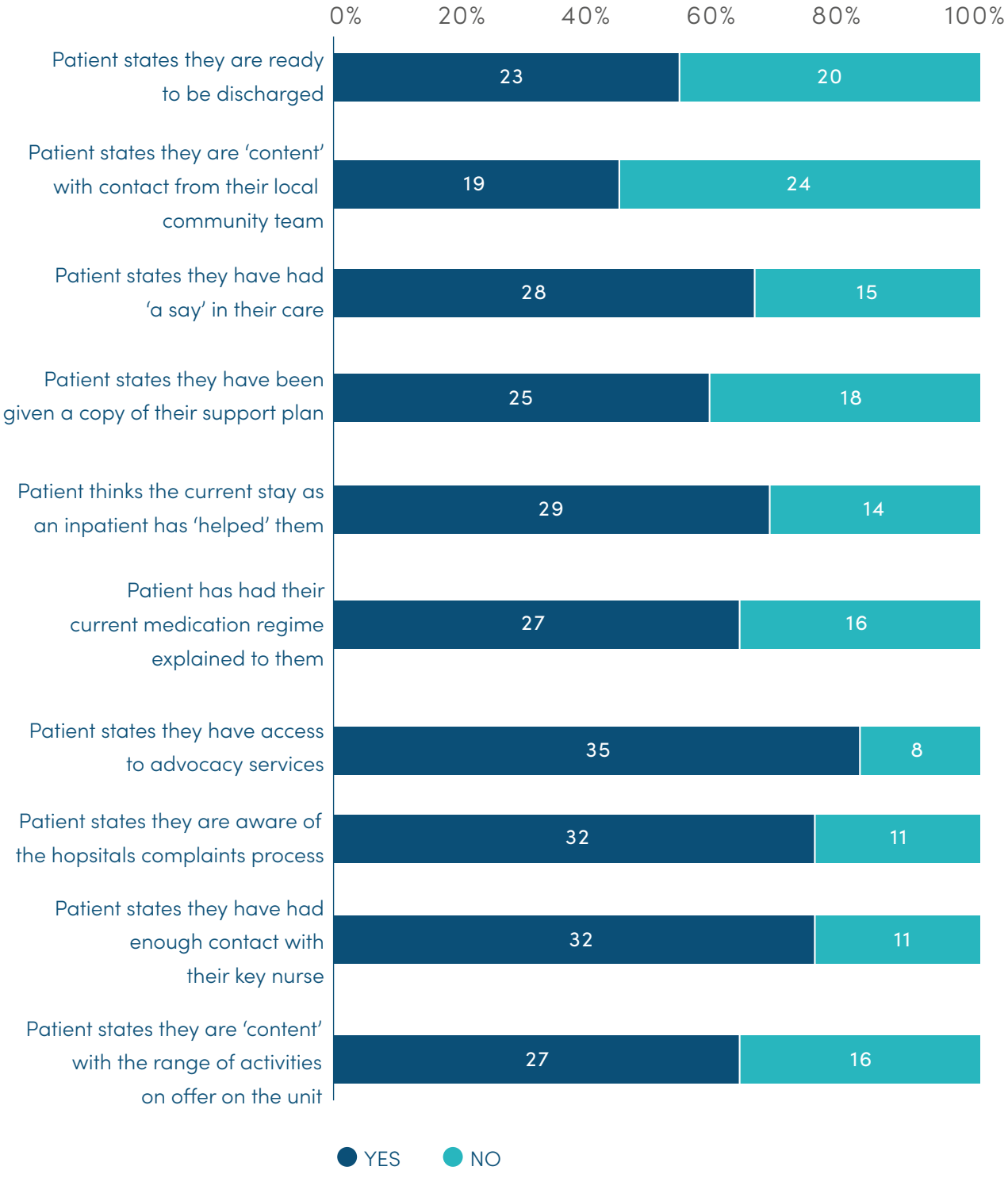
- Asking all patients with capacity a set of 'yes or no' satisfaction questions.
- Working with an independent advocacy service to support a small group of patients to respond to open questions about their experiences.

27.2 Patient Satisfaction

Through discussion with hospital staff, 89 patients were identified as having capacity to participate. Of these 89 patients, 43 patients were available and agreed to partake in the survey. These 43 were subsequently asked ten 'yes or no' questions.

Figure 106 presents the 43 responses to the ten 'yes or no' questions. On average, across all questions, the majority of responses (28, or 65%) were positive.

Figure 106:
Patient Responses to Ten Yes/No Questions



27.3 Patient Experience

This National Care Review partnered with advocates working for an independent service which provided regular support to hospital patients. Advocates met individually with seventeen patients and completed a bespoke, co-designed questionnaire to gain insight into individual experience, satisfaction, expectation and opinion.

The questions covered four broad themes, such as:

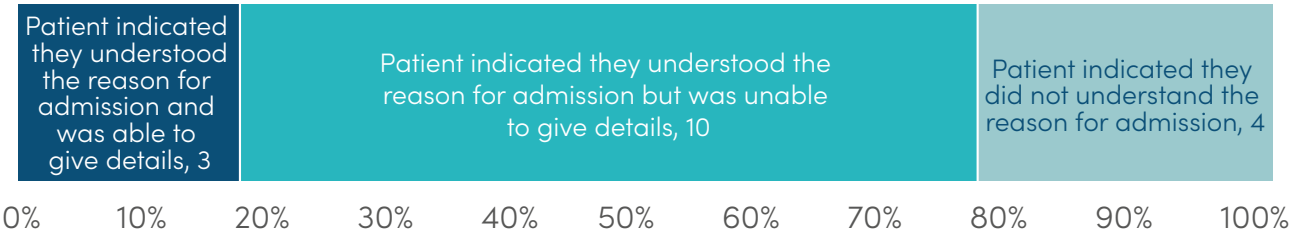
- The patients' understanding of the reasons for admitted to hospital.
- The patient's experience of care and treatment being received.
- The patients feeling empowered and capable of raising concerns or seeking additional support.
- The patients' plans on discharge.

Each of these areas is discussed below.

27.4 Circumstances of Admission

Figure 107 presents the number of patients able to articulate the reasons supporting their current hospital admission.

Figure 107:
Patient Response to Comprehension of Admission Question

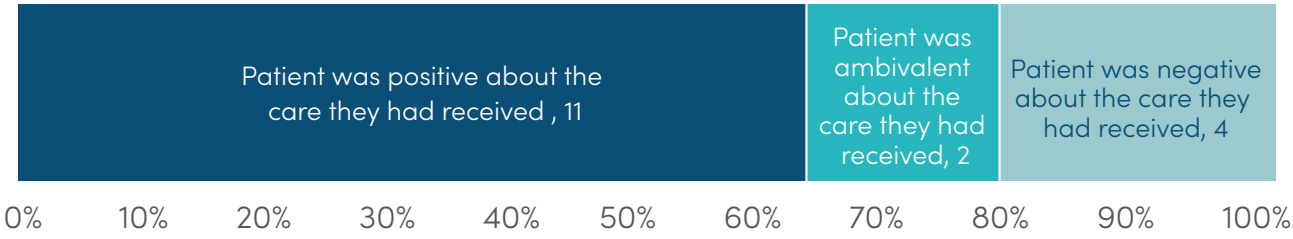


When asked about what was 'important' regarding their stay in hospital, patients stated that they needed to '*get better*', have '*treatment*' or '*move on*'. Maintaining family contact was also important for many patients.

27.5 Experience of Care

Figure 108 presents the number of patients who expressed a particular opinion about the care they received.

Figure 108:
Patient Response to Opinion of Care Question



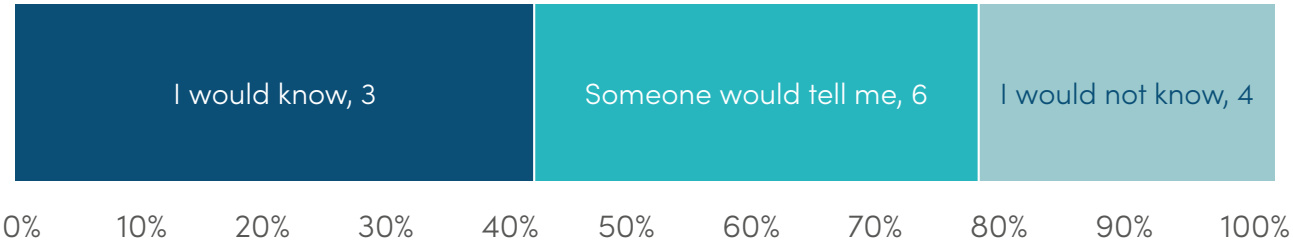
The majority of the 17 patients (10, or 59%) stated that they would like things to be '*different*', mostly in relation to having '*more support*' or '*more freedom*'.

The majority of the 17 patients (10 or 59%) stated that their needs were either '*fully*' or '*partially*' being met, whilst 6 patients (35%) stated that their needs were not being met and 1 patient (6%) '*did not know*'.

27.6 Expectations

It is empowering for patients to recognise where they are on their personal care journeys. Figure 109 presents the number of patients expressing a particular opinion about how they would know if they were 'making progress'.

Figure 109:
Patient Response to Change Question

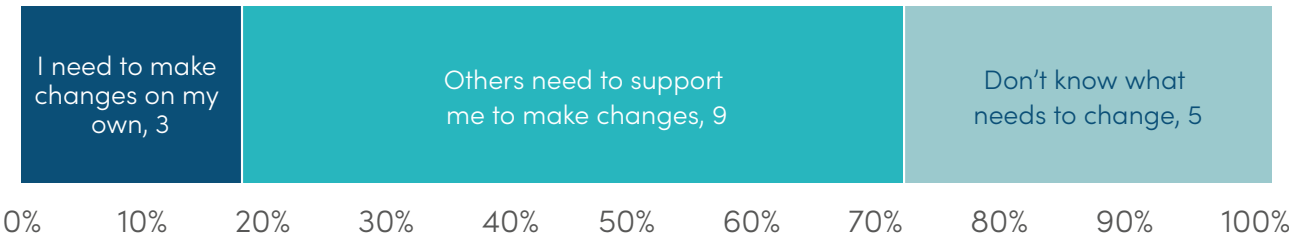


Patients were asked if they had ever felt '*frustration*' over their progress. Of the 17 patients, 7 (41%) stated that they did feel '*frustration*' and 10 (59%) said they '*did not*'.

Patients were asked to discuss the 'next step' in their personal care journey. The majority of the 17 patients (12, or 71%) stated that they wanted to be cared for in the community or to '*step down*' to the next tier of care, and 5 patients (29%) had '*no plans*' for the future other than remaining in hospital.

Figure 110 presents the number of patients expressing a particular opinion when asked what '*needed to change*' and whether they required the '*support of others*' to change in order for progress to be made.

Figure 110:
Patient Response to Comprehending Their Own Progress



27.7 Raising Concerns

Advocacy services support and enable patients who have difficulty representing their own interests to exercise their rights, express their views or explore and make informed choices.[178]

Patients were asked if they knew how to 'get help' if needed. The majority of the 17 patients (16, or 94%) were able to identify appropriate ways to seek additional help if they had an issue, and responses included advocates, unit staff or hospital management.

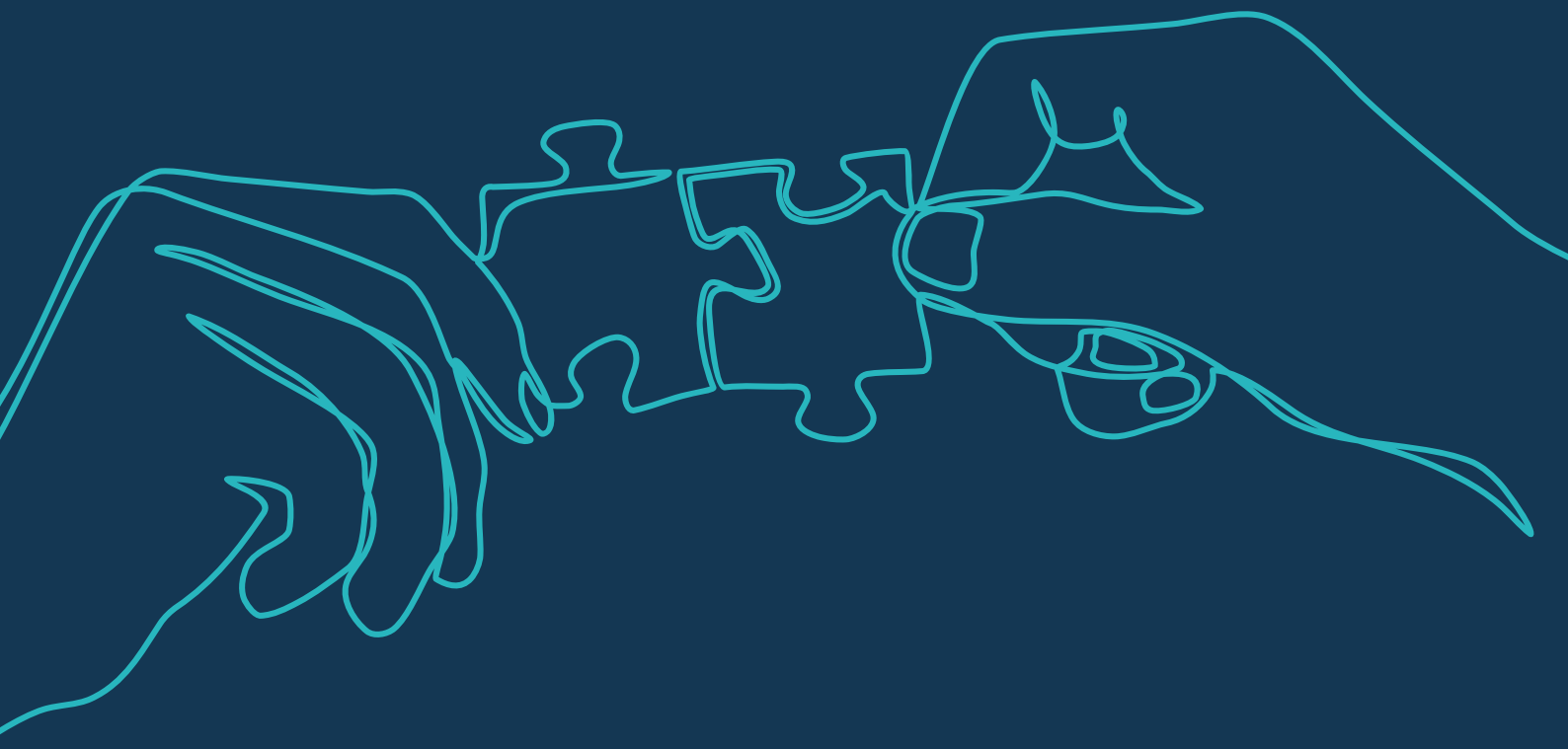
The majority of the 17 patients (15, or 88%) stated that they had made use of the advocacy service. Patients stated that they had used the advocacy either to help with an issue, obtain support with meetings, to '*chat*' or to listen.

National Care Review Recommendations

48) **Commissioners should ensure that patients, families and carers have a voice in service design.**
49) **Providers should undertake regular patient experience surveys, in partnership with independent advocacy services, and use the findings of these surveys to improve care.**
50) **Commissioners should ensure that measures of patient satisfaction are obtained and used, as an indicator of responsive and quality services.**

PART D
Ready to Care

'Work to ensure safety and to enable satisfactory outcomes must go alongside a drive to consistently provide care which is compassionate and sensitive to personal need.' [179]



28. Environment of Care

There is an expectation that the environment is of an appropriate design and fit for purpose in terms of comfort, safety and security, and that furniture and decor within the environment is in a good state of repair.[180]

The patients within the scope of this National Care Review were cared for in 55 units across 36 hospital sites. In 44 of these units, an environmental and staffing questionnaire was completed by staff as part of this Review.

This National Care Review found that 22 of the units (50%) had been purposely designed and built for patients with learning disabilities, and 22 (50%) had not.

In terms of décor, 38 units (86%) could be described by staff as having a '*modern décor*' and 6 units (14%) were described as having a '*tired*' look.

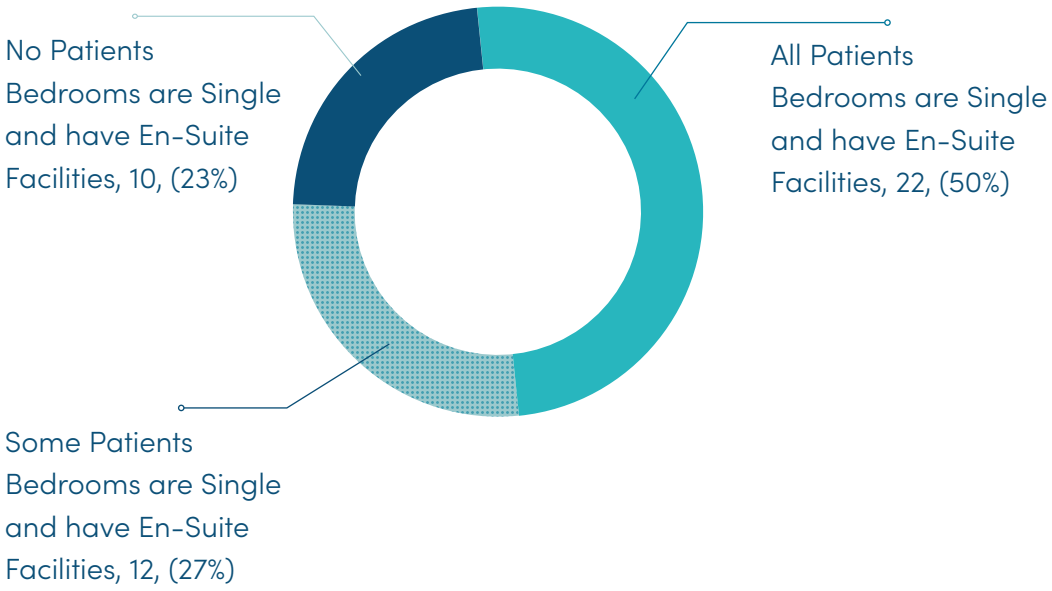
27 units (61%) had been redecorated within the previous year, 14 units (32%) had been redecorated within the previous three years, and 3 units (7%) had not been decorated for over three years.

28.1 Privacy & Dignity

Studies have shown that patients reported more privacy, dignity and confidentiality, felt more able to disclose '*sensitive information*' to staff, and had improved sleep when single bedrooms were provided.[181]

Figure 111 presents the number of units with single bedrooms and en-suite facilities.

Figure 111:
Number of Units With Single Bedrooms & En-suite Facilities



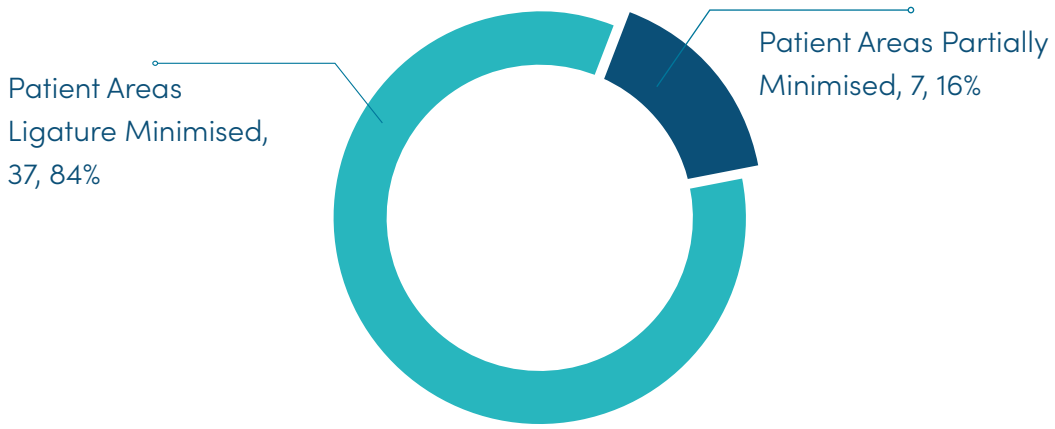
28.2 Ligature minimised environment

'*Three-quarters*' of patients who kill themselves while on a psychiatric unit do so by hanging or strangulation.[182] A ligature anchor point is anything which can be used to attach a cord, rope or other material for the purpose of hanging or strangulation. Ligature anchor points include shower rails, coat hooks, pipes and radiators, bedsteads, window and door frames, ceiling fittings, handles, hinges and closures.[183] It is difficult to remove every potential ligature anchor point, which is why areas are described as 'ligature minimised' not 'ligature free'.

This National Care Review looked at whether the environment on each unit had been intentionally ligature minimised. This review asked whether the entire unit was ligature minimised, or only certain areas such as bedrooms and bathrooms.

Figure 112 presents the number of units ligature minimised and shows that 100% of units had been wholly or partially ligature minimised.

Figure 112:
Number of Units & Ligature Minimisation Status



Staff need to be constantly vigilant and undertake regular assessments of areas in order to identify and remove ligature anchor points.[184]

This National Care Review looked at whether an audit was undertaken on a regular basis to assess the environment for new ligature anchor points, and found that staff on 43 units (98%) undertook such an audit at least once a year and staff on 1 unit (2%) did not.

28.3 Empowerment

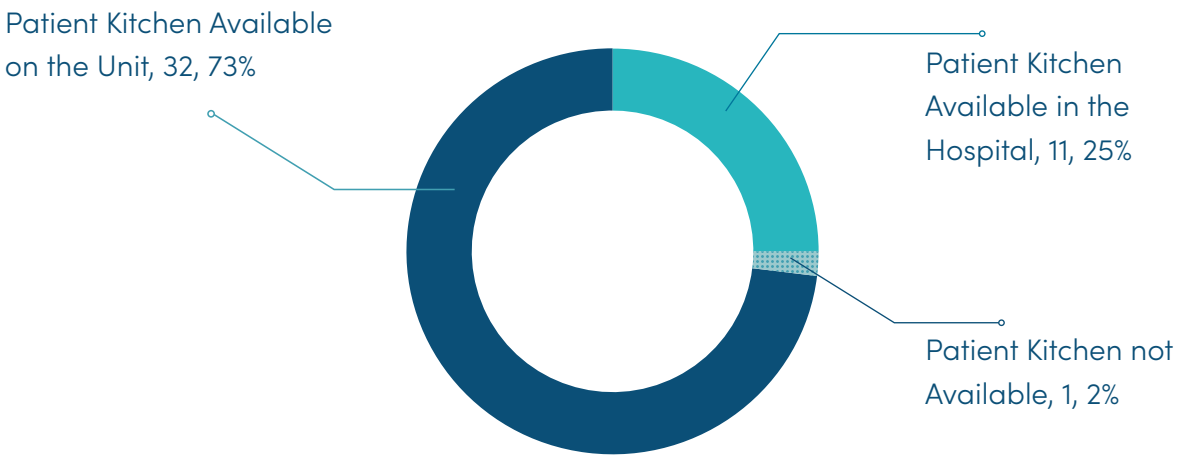
Underweight, overweight and obesity issues are more prevalent in individuals with a learning disability than in the general population.[185]

Obesity is a major physical health issue for patients who have a learning disability. Weight gain can be caused by side-effects of medication, lack of exercise and/or poor diet. It is therefore important that staff promote healthy living through exercise and educate patients about healthy food and '*how to cook healthy food*'.[186]

'Patients' kitchens', also called 'Activity of Daily Living' kitchens provide an important resource and enable patients to practice functional tasks related to meal preparation and cooking. For the patient, this can be an opportunity to learn new skills and/or maintain existing cooking skills.[187]

This National Care Review looked at whether patients had access to a specially designed and dedicated 'patients' kitchen'. Figure 113 presents the number of units who had a 'patients' kitchen', and whether access to the 'patients' kitchen' was away from the unit but within the hospital grounds.

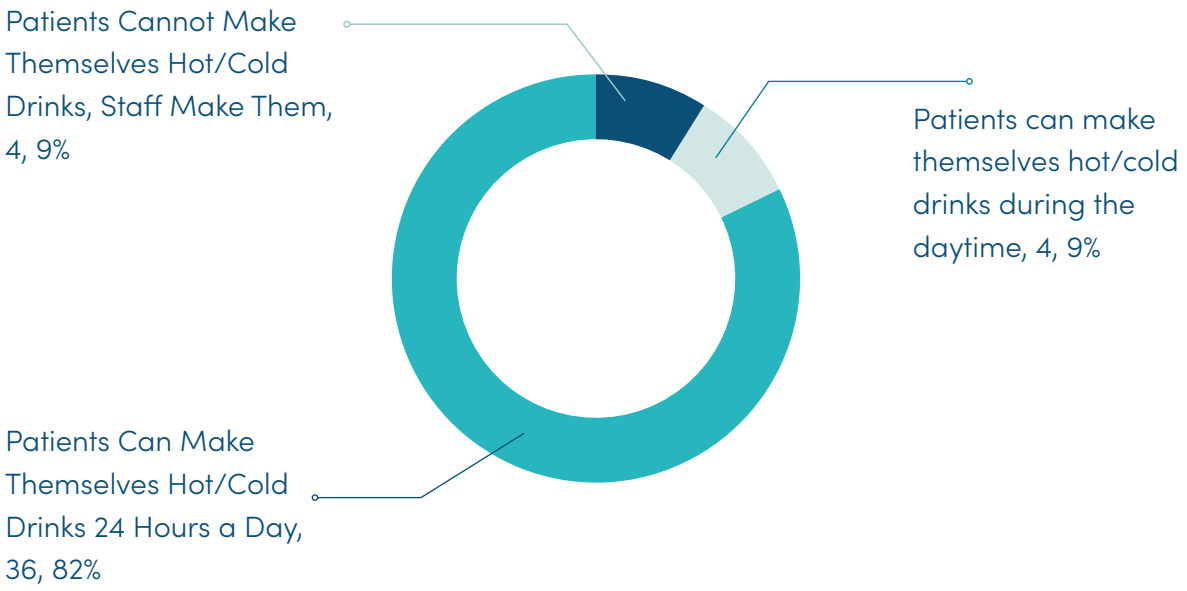
Figure 113:
Patient Kitchen Access



When in hospital, individuals with a learning disability should have access to fresh air, exercise, and healthy food.[188] This National Care Review confirmed that all patients had access to a shared or dedicated garden.

There is an expectation that providers of care ensure that patients have access to hot and cold drinks within '*reasonable hours*', and that patients are encouraged to prepare their own drinks after appropriate risk assessment.[189] Figure 114 presents the number of units who enabled patients to access a self-service drink facility.

Figure 114:
Units Who Ensured Patients can Access a Self-Service Drinks Facility



National Care Review Recommendations

52) **Providers should ensure that their environments of care are safe, high quality, fit for purpose, and repaired and redecorated when necessary.**
53) **Providers should ensure that patients have access to a 'patient's kitchen' and hot and cold drinks, after appropriate risk assessment.**

29. Levels of Care

The Nurse Staffing Levels (Wales) Act requires the Welsh Government to set out the methods by which the NHS is expected to determine appropriate nurse staffing levels to meet patients' needs in the services they commission and provide.[190]

In order to determine appropriate staffing levels, it is essential to understand the intensity of care delivery required for the patient cohort being managed by staff. The National Collaborative Commissioning Unit has developed a 'safety' Level of Care and an 'activity' Level of Care that measure and score the intensity of staff input required to ensure that the patient's safety is maintained or that the patient engages in activities successfully. These 'Levels of Care' can also be a proxy for acuity and can be useful in benchmarking and evaluation.

Each Level of Care is scored from 5 (highest level of staff input required to meet the patient's needs) to 1 (lowest level of staff input required to meet the patient's needs). Each score has one to three sub levels to give greater detail.

29.1 Safety-Level of Care

Patient safety is concerned with any issue, separate to the natural progression of the patient's illness or injury, experienced during a patient's admission which could or did cause harm. [191] Some patients with a learning disability need to be observed for their own, or others, safety.[192]

The Safety-Level of Care describes the staff involvement required to minimise the possibility of the patient harming themselves or others. The Safety-Level of Care also describes the staff input required to ensure that the patient can access the community safely.

This National Care Review recorded the Safety-Level of Care for each patient on the day of audit, although the Level of Care can change depending on the presentation and needs of the patient.

Figure 115 presents the number of patients within each main level of the Safety-Levels of Care.

Figure 115:

Safety-Level of Care, Number of Patients by Gender in Each Level

Level	Safety-Care Area	Male	Female
5	Continuous observation/support - 1:1 or above - for 24 hours/ day due to risk of harm to self	23 (20%)	7 (13%)
	Continuous observation/support - 1:1 or above - for 24 hours/ day due to risk of harm to or from others		
	Continuous Observation/support - 1:1 or above - for 24 hours/ day due to vulnerability or inability to communicate		
4	Observation within the unit during specific periods or specific areas (daytime/night time/communal areas/bedroom, etc) - 1:1 or above - due to risk of harm to self	26 (23%)	13 (25%)
	Observation within the unit during specific periods or specific areas (daytime/night time/communal areas/bedroom, etc) - 1:1 or above - due to risk of harm to or from others		
	Observation within the unit during specific periods or specific areas (daytime/night time/communal areas/bedroom, etc) - 1:1 or above - due to vulnerability or inability to communicate		
3	Potential risk of harm to self and requires prescribed intermittent observation	43 (38%)	21 (40%)
	Potential risk of harm to or from others and requires prescribed intermittent observation		
	Community access requiring dedicated support at 1:1 or above due to risk to self/others		
2	Escorted community access only	19 (17%)	10 (19%)
	Individual requiring cohorted (group) supervision		
	Requires minimal/general observation, ongoing support, reassurance or intervention		
1	Unescorted community access	3 (3%)	1 (2%)
	Requires no specific supervision within the unit		

This National Care Review found that the average Safety-Level of Care was 3. Figure 116 presents the average Safety-Level of Care for patients across each type of provider, by gender. The Figure shows that the average Safety-Level of Care for male patients in low secure was lower than in other types of provider, which could signify that these patients may not require this type of care for issues of safety.

Figure 116:

Average Safety-Level of Care by Gender & Type of Provider

	Medium Secure	Low Secure	Controlled Egress	Assessment & Treatment	Uncontrolled Egress	Continuing Care
Average	**3.3**	**2.8**	**3. 3**	**3.5**	**3.4**	**3.5**
Male	3.3	2.6	3. 5	3.5	3.4	3.7
Female		3.3	3. 1	3.5		3.1

This National Care Review also enables the recording of the highest Level of Care for each patient [see box]. This enables the consideration of the continued requirement for a specific type of provider, for example a patient on Level of Care 2 in a medium secure unit may be considered for transition to a low secure unit. Any patient on Level of Care 1 in hospital may be considered for transition, although many other factors should be taken into account when determining the appropriate environment for a patient.

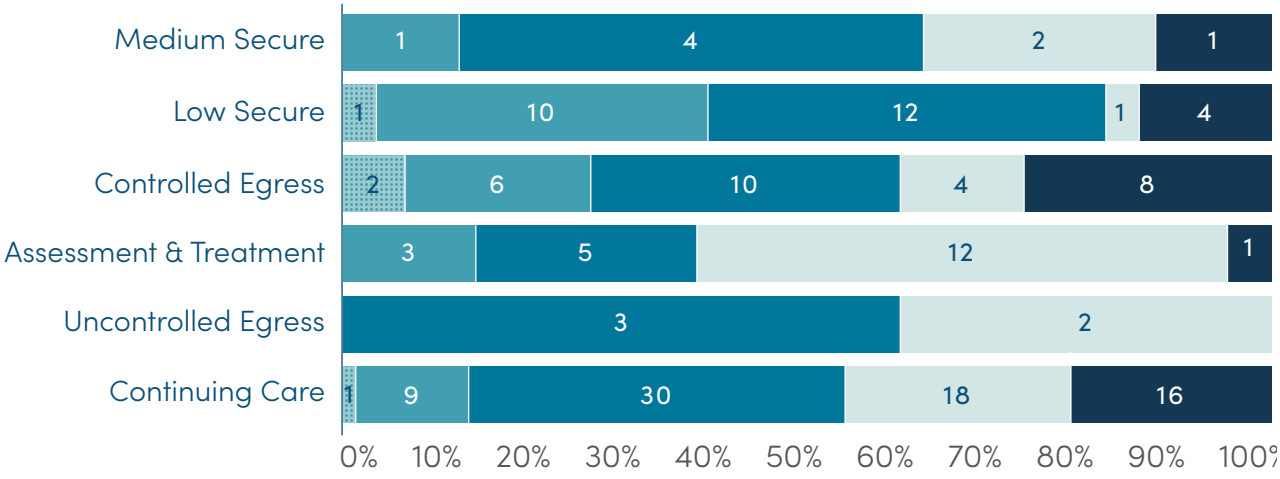
Figure 117 presents the Safety-Level of Care by the highest level for each patient, by type of provider.

Safety-Levels of Care

The Safety-Levels of Care must be used with due regard to environmental, relational and procedural security in place within each type of provider. As an example a typical medium secure unit may have environmental features that reduce the risk of a patient leaving unplanned that may not be present in a continuing care unit, therefore the Safety Level of Care may be higher for patients at risk of leaving unplanned in a continuing care unit as staff observation may be required to manage this risk.

Figure 117:

Number of Patients in each Safety-Level of Care by Type of Provider



29.2 Activities - Level of Care

It is essential for the health and well-being of an individual with a learning disability that they participate in a broad range of meaningful activities.[193] Patients should have opportunities to learn, contribute, and build friendships and relationships, in order to improve their quality of life and reduce behaviours that challenge.[194]

The Activities-Levels of Care describes the staff involvement required to ensure that the patient's personal care needs are met. It also describes the staff input required for the promotion of independence and self-resilience.

This National Care Review recorded the Activities-Level of Care for each patient on the day of audit, although the Level of Care can change depending on the presentation and needs of the patient.

Figure 118 presents the number of patients within each main level of the Activates-Levels of Care.

Figure 118:
Activity Level of Care, Number of Patients by Gender in Each Level

Level	Activities-Care Area	Male	Female
5	Totally dependent for all activities of living as unable to participate in own care	10 (9%)	4 (8%)
4	Requires care from minimum of 2 staff for nearly all activities of daily living , manual handling, repositioning	9 (8%)	6 (12%)
3	Requires care from 1 staff for nearly all activities of daily living, manual handling, repositioning	19 (17%)	5 (3%)
	Requires assistance with personal care lasting more than an 30 mins		
	Requires assistance with mobility, repositioning with 1-2 staff and use of aids		
2	Requires assistance with some activities of daily living	39 (34%)	23 (44%)
	Individual requiring prompting with most or all activities of daily living		
	Assistance with feeding or fluid management		
1	Individual requiring prompting with some activities of daily living	37 (32%)	14 27%)
	Self-caring/ independent		
	Mobile, with/without use of aids		

This National Care Review found that the average Activities-Level of Care was 1.9. Figure 119 presents the average Activities-Level of Care for patients across each type of provider, by gender.

Figure 119:
Average Activity Level of Care by Gender & Type of Provider

	Medium Secure	Low Secure	Controlled Egress	Assessment & Treatment	Uncontrolled Egress	Continuing Care
Average	**1.3**	**1. 4**	**1. 7**	**2. 4**	**1. 8**	**2. 9**
Male	1.3	1.3	1.9	2.7	1.8	2.9
Female		1.6	1.4	2		3

Figure 119 shows the average Activity-Level of Care was higher in assessment and treatment units and continuing care units than in other types of provider indicating a lower degree of independence for patients cared for in these units.

This National Care Review also enables the recording of the highest Activities-Level of Care for a patient [see box]. This enables consideration of the continued requirement for a specific type of provider. A patient on Level of Care 1 is relatively independent of staff support and can be considered for transition, although many other factors should also be taken into account when determining the appropriate environment of care for a patient.

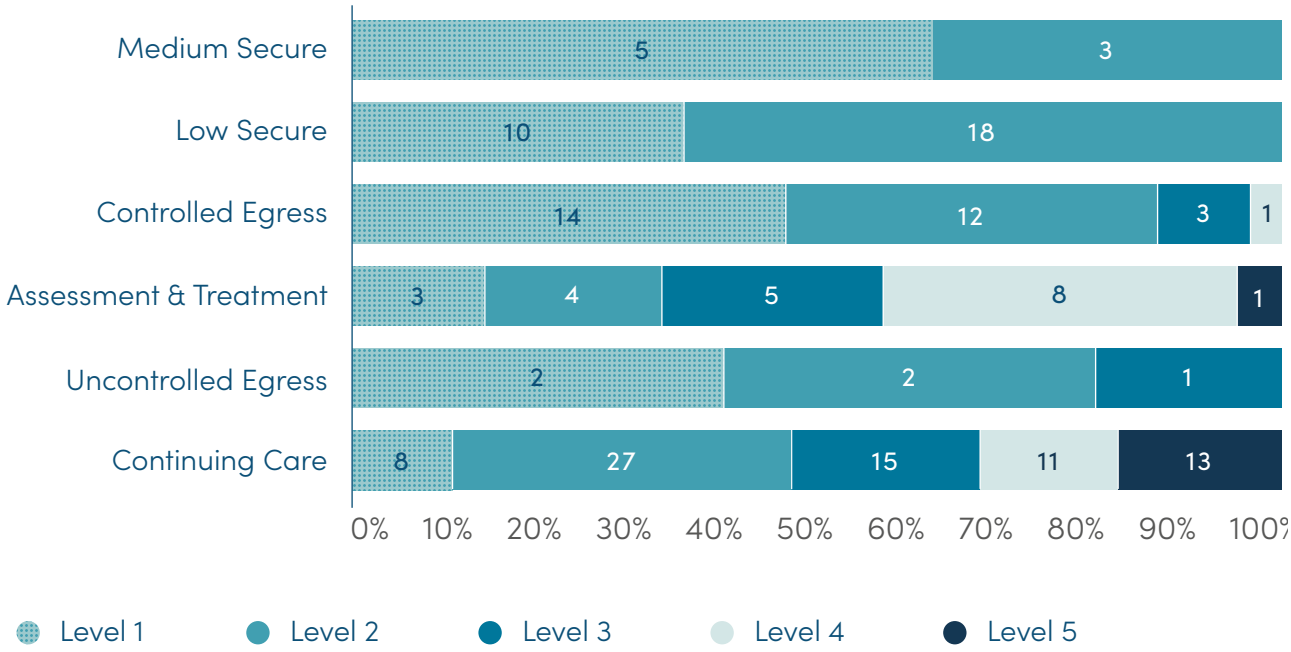
Activities-Levels of Care

The Activities-Levels of Care is a useful indicator of the dependency, autonomy, frailty and vulnerability of a patient. It indicates staff required to deliver personal care or support.

Figure 120 shows the Activities-Level of Care by the highest level for each patient, by type of provider.

Figure 120:

Number of Patients in Each Level of Activity Level of Care by Type of Provider



Activities delivered to patients need to be meaningful, not valueless distractions. Previous reports in Wales have found that some activities being offered to patients '*provided little opportunity for stimulation*' and '*did not improve*' independent living skills.[195]

29.3 Safety & Activities Level of Care

In order to get a general overview of the patient needs which require staff input, the Safety-Level of Care and Activities-Level of Care can be cross-referenced. Figure 121 presents the cross-referenced Levels of Care.

Figure 121:

Number of Patients in each Level of Activity or Safety Level of Care

		Activities				
		5	4	3	2	1
Safety	5	5 (3%)	4 (2%)	9 (5%)	7 (4%)	5 (3%)
	4	5 (3%)	2 (1%)	9 (5%)	17 (10%)	6 (4%)
	3	4 (2%)	8 (5%)	5 (3%)	28 (17%)	19 (11%)
	2		1 (1%)	1 (1%)	9 (5%)	18 (11%)
	1				1 (1%)	3 (2%)

Figure 121 shows that 32 patients (19%) have a cross-referenced Safety and Activities Level of Care of 1/1, 2/1, 1/2 and 2/2. These Levels of Care indicate that their needs could be managed in a non-hospital environment, although other factors should also be taken into account when determining the appropriate environment.

National Care Review Recommendations

53) **Commissioners should ensure that patients with low Levels of Care, which demonstrate that a less restrictive environment could meet their care needs, are considered for transition.**

54) **Providers should review, record and discuss the patient's Level of Care on a monthly basis to support recording of progress.**

30. Staffing

In learning disability hospitals, there must be sustainable staffing capacity and capability to provide safe and effective care to all patients at all times.[196] These staff should be well-trained and have the '*right values and approach*' to work with individuals with a learning disability and their families.[197]

30.1 Nurse Staffing

The number of staff on a particular unit at a particular time must be based on patient needs, and there should be sufficient registered nurses to deliver high quality care at all times without over-reliance on agency staff.[198]

The number of registered learning disability nurses deployed on each unit for specific shifts was considered as part of this National Care Review, but there are a number of other staff, mainly healthcare support workers, that constitute part of the typical unit workforce. These staff have not been considered as part of this review, as the numbers deployed on each shift differ extensively between units, depending not only on the acuity of patients but the service function, operation, size and design.

Welsh hospital regulations do not explicitly state that a registered nurse must be present on each unit at all times,[199] unlike standards in place for commissioned services under the National Framework Agreement.[200]

This National Care Review found that 41 of the 44 units (93%), where a questionnaire was completed, had at least one registered nurse on each day shift, and 38 (86%) had at least one registered nurse on each night shift.

This National Care Review found that the average number of registered nurses per day shift was two, whilst for night shifts it was one. Figure 122 presents the lowest, highest and average number of registered nurses on units per shift.

Figure 122:
Average Number of Registered Nurses Working on Units for Specific Shifts

	Registered Nurses on Each Day Shift During Weekdays	Registered Nurses on Each Day Shift During Weekends	Registered Nurses on Each Night Shift During Weekdays	Registered Nurses on Each Night Shift During Weekends
Lowest number	0	0	0	0
Highest number	4	4	3	3
Average Number	2	2	1	1

A patient who does not require care to be delivered or supervised by a registered nurse can be considered for transition to community services with similar staffing levels, although many other factors should also be taken into account when determining the appropriate environment of care for a patient.

Staffing by registered nurses and healthcare support workers should be complemented by other professionals such as therapy staff.

Commissioners should monitor delivery of safe and sustainable staffing levels by providers which reflects safe, effective, caring, responsive and well-led care on a sustainable basis.[201]

30.2 Therapists

In order to achieve the outcomes that underpin the reason for admission, and to meet the complex needs of individuals with learning disabilities, it would be expected that an extensive therapy team is employed. The members of this team formulate, assess, treat and review clinical, therapeutic and psychosocial interventions to provide effective, evidence-based care within a culture of positive regard and hope.

A learning disability may affect the way in which an individual is able to understand and communicate information.[202] Assessment and treatment for communication issues may be provided by specialist speech and language therapists or may be augmented by '*communication passports*' or '*adapted communication systems*'.[203]

Psychological therapies should be appropriate to the cognitive and communication needs of the individual with a learning disability. Specific psychological therapies for individuals with mental health needs, such as cognitive behaviour therapy may be appropriate for individuals with a learning disability but would generally require delivery in adapted formats.[204]

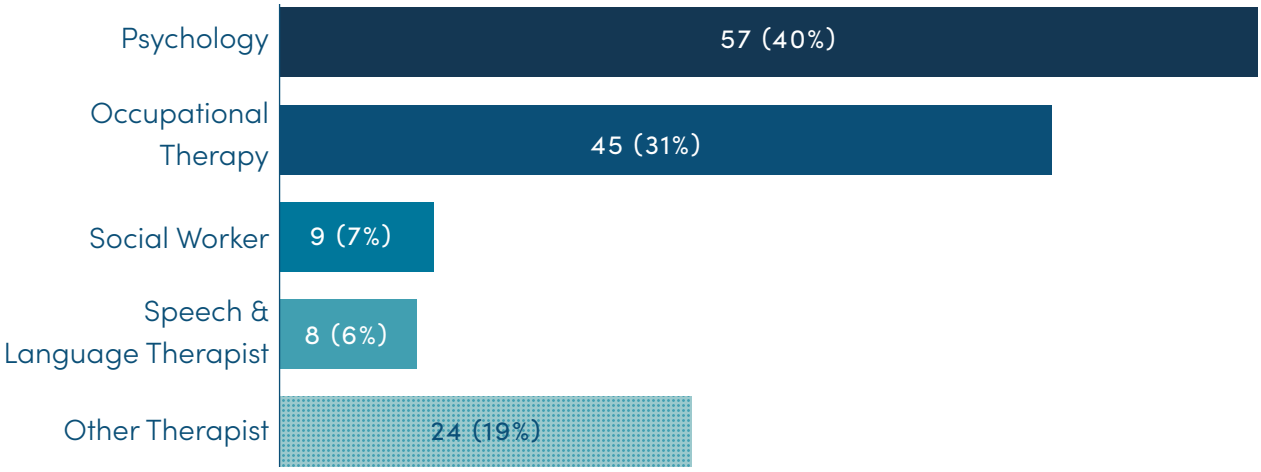
Assessment of an individual's sensory needs and functional skills, and the development and delivery of interventions to improve independence and quality of life, are often identified as important components of a patient's treatment programme and are delivered through occupational therapy services.[205] Studies have concluded that occupational therapists make '*significant contributions*' to improving the lives of patients with a learning disability.[206]

This National Care Review looked at each patient's regular access to non-nursing and non-medical staff, collectively termed 'therapists' for simplicity in this Review. The different type of therapists were sorted into the following five groups:

- Psychologists (such as clinical psychologists and psychology assistants).
- Occupational therapists (such as occupational therapists and occupational therapy assistants).
- Social workers (delivering dedicated family support).
- Speech & language therapists.
- Other therapists (such as nurse therapists, psychiatrists delivering therapy and art therapists).

This National Care Review found that 143 therapy sessions were delivered to patients on a regular basis. Figure 123 presents the proportion of 'therapy sessions' delivered, by type of therapists.

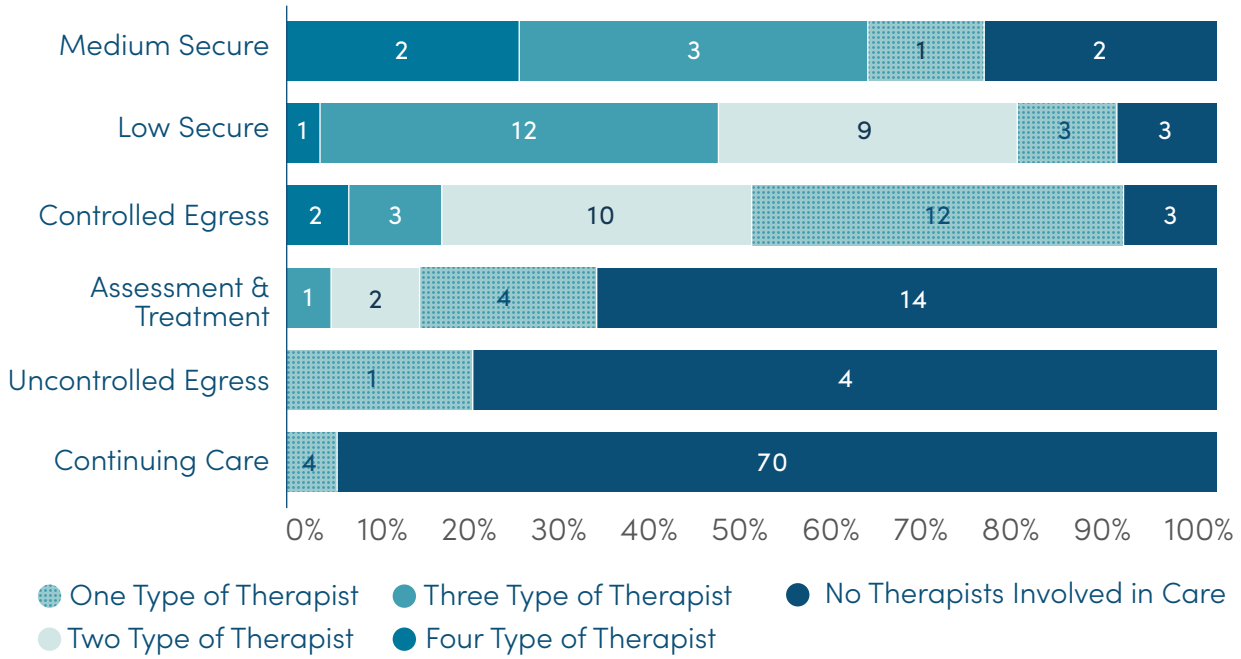
Figure 123:
Number of Therapy Sessions Delivered By Specific Therapists



This National Care Review found that 70 patients (42%) had access to one or more therapists as part of their treatment. Figure 124 presents the number of patients who had no access to a therapist and those who had access to one, two, three or four different type of therapists, by type of provider. The Figure shows that the type of provider where patients had most access to one or more therapists on a regular basis was controlled egress (90%), and the least access was in continuing care (5%).

Figure 124:

Number of Patients Having Access to Different Type of Therapists by Type of Provider



This National Care Review did not have the remit to audit the quality of the input delivered by the therapists, although previous reports in Wales have found that some activities being offered to patients provided '*little opportunity for stimulation*', and did not improve '*independent living skills*'.[207]

There is an expectation that all providers should ensure that there is a broad range of meaningful activities available for each patient and that these activities support or address the patient's individual strengths, needs, preferences and aspirations wherever possible and reasonably practicable. These activities should be delivered by suitably qualified therapy staff on an individual and group basis.[208]

30.3 Staff Training

Staff should ensure that they maintain and develop the knowledge and skills required to meet the patients' needs. Staff should participate in professional development as part of maintaining their commitment to ensuring the delivery of safe and high-quality care, as well as to fulfill personal registration requirements.

A recent report has stated that there are '*too many*' learning disability hospitals where staff lack the skills, training, experience or clinical support to care for patients adequately.[209]

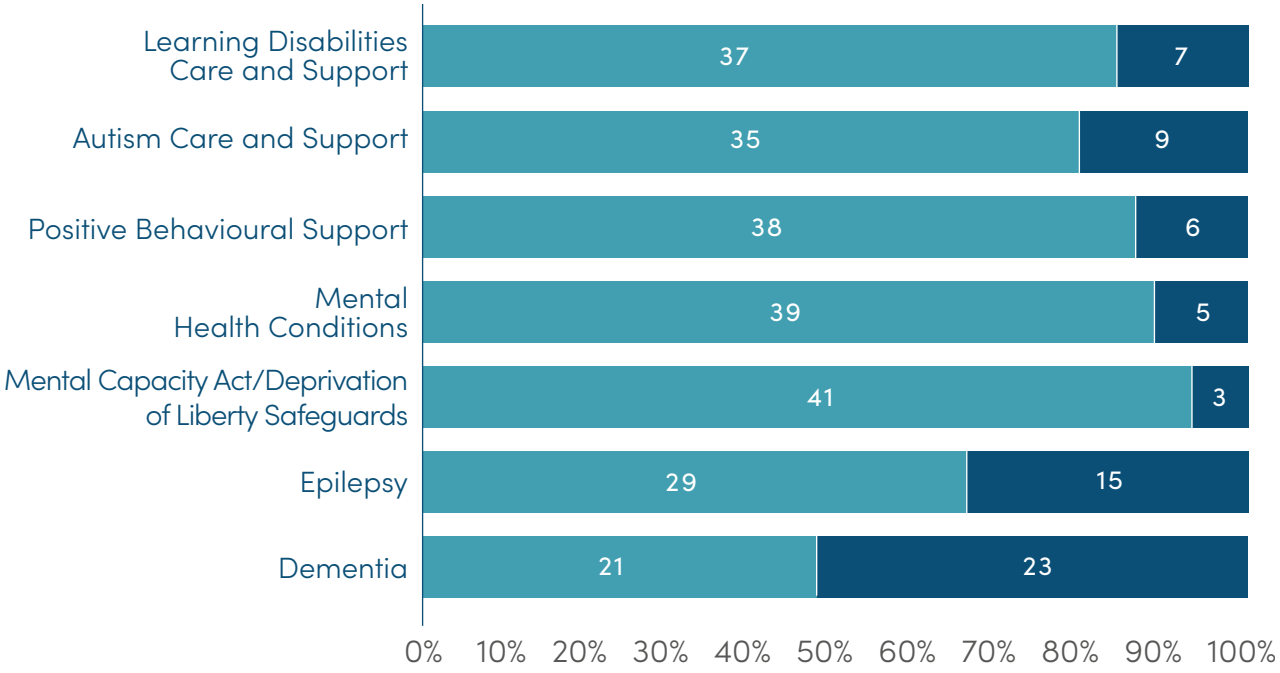
This National Care Review looked at the number of hours training that staff had undertaken per year in the following seven areas:

- Learning Disabilities Care and Support.
- Autistic Spectrum Disorder Care and Support.
- Positive Behavioural Support.
- Mental Health Conditions.
- Mental Capacity Act/Deprivation of Liberty Safeguards.
- Epilepsy.
- Dementia.

Some providers stated that they adapted the staff training regime and introduced new training to meet the needs of the current patients.

Figure 125 presents the number of units where staff have received some training in specific areas.

Figure 125:
Proportion of Units Offered Training in Specific Areas



National guidance has promoted the provision of training about signs and symptoms of autistic spectrum disorders.[210] Some commissioners have introduced actions to ensure that all health and care staff have a degree of training about patients with learning disabilities and/or autistic spectrum disorder.[211]

'Positive Behaviour Support' is a person-centred framework for providing support to individuals with a learning disability who have developed, or may be at risk of developing, behaviours that challenge. It is a '*blend of person-centred values and behavioural science*' and uses evidence to inform decision-making.[212]

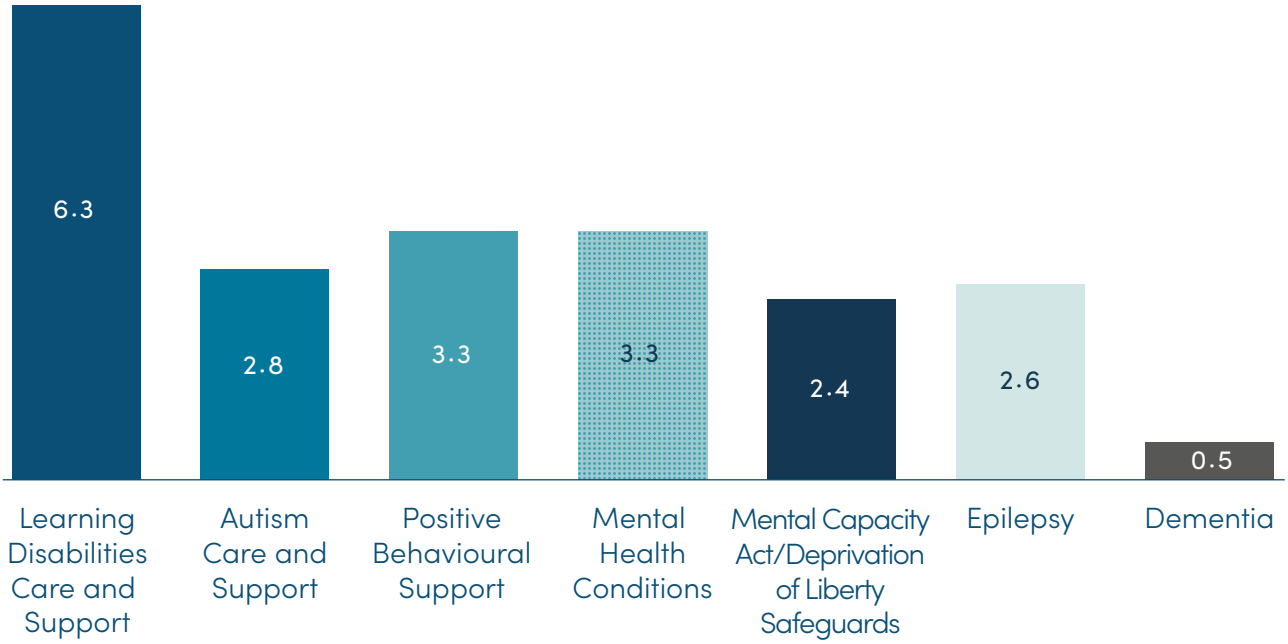
A recent report has stated that a lack of understanding and confusion around the Deprivation of Liberty Safeguards remains one of the primary reasons for poor practice in this area among providers, and that '*in-depth*' and '*practical*' training is required.[213]

Epilepsy should be a core part of all learning disability nurse training, as staff are '*likely to encounter*' epilepsy as part of their work.[214]

As the life expectancy of individuals with a learning disability is increasing, both they and the individuals and organisations that support them will need to know more about dementia.[215]

Figure 126 presents the average number of hours training in specific areas offered to staff, per year.

Figure 126:
Average Number of Hours of Staff Training in Specific Areas



It is Welsh Government policy to ensure a sufficiently valued and skilled workforce to ensure excellent standards of care.[216] Providers should ensure that staff are competent, supervised, supported, trained and equipped to deliver high-quality and safe care.[217]

National Care Review Recommendations

55) **Commissioners should ensure that providers have sufficient levels of staffing to provide safe and progressive care.**
56) **Providers should ensure that they regularly review and revise each unit's staffing requirements to ensure that the needs of patients are met.**
57) **Commissioners should ensure that any outcomes which require contribution by therapy staff are being addressed.**
58) **Providers should ensure that the patients have access to staff with specific skills, training and experience to enable them to achieve optimal functioning and well-being.**
59) **Providers should ensure that all staff are delivering high quality, evidence-based interventions to achieve the patient outcomes.**

PART E
The Patient's Journey

'A move to the community is linked to an improved quality of life for people with learning disabilities.' [218]

31. Institutionalisation

Studies have stated that patients who have been in hospital for many years may be institutionalised, with '*little choice or control over their care*' and excluded from mainstream services.[219] Studies have stated that some patients become '*stuck*', with the '*negative effects*' of the inpatient environment '*causing a vicious cycle of increasingly challenging behaviour, and increasingly unlikely discharge*'.[220]

Figure 127 compares the patient's length of stay with the patient's age, in order to determine the proportion of their lives they have spent as an inpatient. This Figure is an indicator not a measure, as institutionalisation is a result of interaction between hospital environment, severity of patient symptoms and the manifestation of behaviours that are not part of the disability itself.[221]

Figure 127:
Patient's Length of Stay in Age Bandings

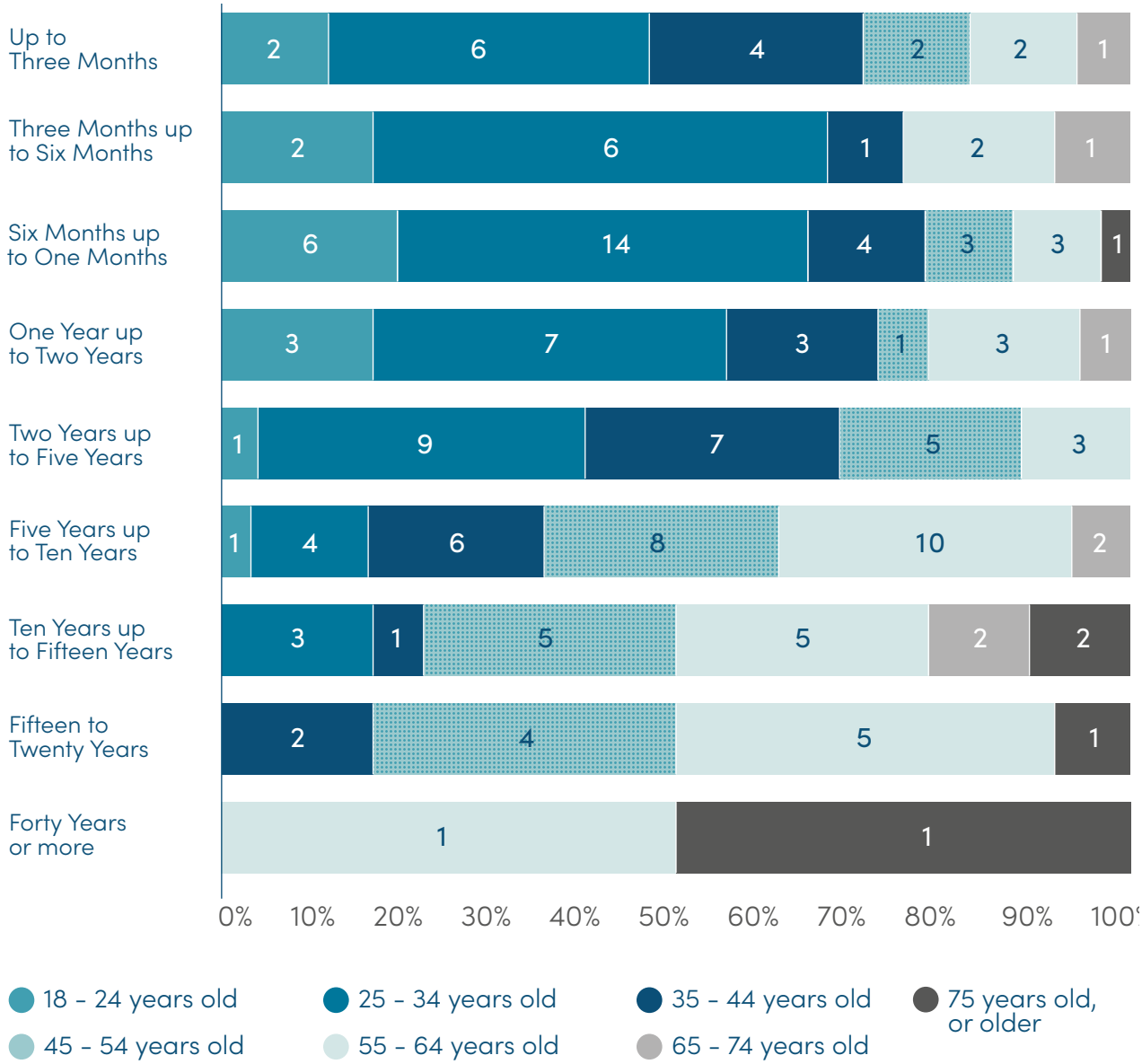


Figure 127 shows that many individuals have spent significant periods of their lives in hospital care, with some having been inpatients since reaching adulthood.

The impact and issues with long term care are not new. In 2001, a major report stated that patients in '*NHS residential campuses*' had '*significantly poorer outcomes*'.[222] A 2016 report stated that many patients in NHS Wales' continuing care units continue to live in the same settings since the '*closure of long stay institutions*', with '*little consideration*' as to whether they are living in the most appropriate setting, and that Health Boards should '*question the purpose of these settings*'.[223]

National Care Review Recommendations

60) **Providers should ensure that all patients are assessed for behaviour that indicates institutionalisation.**
61) **Providers should ensure that the maintenance and promotion of self-advocacy, self-resilience and reduction in dependency is a primary focus of care delivery.**
62) **Commissioners should recognise and address the negative effects and impact of institutionalisation.**

32. Appropriate Environments of Care

One of the objectives set by the Chief Nursing Officer for this National Care Review was to ensure that patients were being cared for in the 'most appropriate' environment of care.

When contemplating whether a patient is ready for discharge or transition to another type of service, many aspects of the patient's history, needs, strengths and aspirations need to be considered.

Studies have shown '*better outcomes*' associated with living in the community rather than in hospital. These outcomes include engagement in community and daily living activities, social contact, quality of the environment, choice and variety of activity.[224]

The patient's community team are crucial to the planning and delivery of a 'seamless' transition. A care co-ordinator must be a '*navigator*' for the patient, aware of '*potential pitfalls*' and '*individual vulnerability*' during transition.[225]

Transitioning patients out of hospital does not mean eliminating all inpatient care. As with the general population, individuals with a learning disability must be able to access hospital support if required.[226] New models of inpatient care may necessitate reduced bed numbers but rapid transition pathways which require integrated planning by health and social care services on a regional level. Specialist provision such as 'secure services' may require planning and delivery on a national level in order to deliver the most effective, high quality and efficient services.

Some providers in England are not projected to invest or expand hospital services, due to the NHS England 'Transforming Care' programme which is planning to transition patients out of hospital settings and into community services. [227]

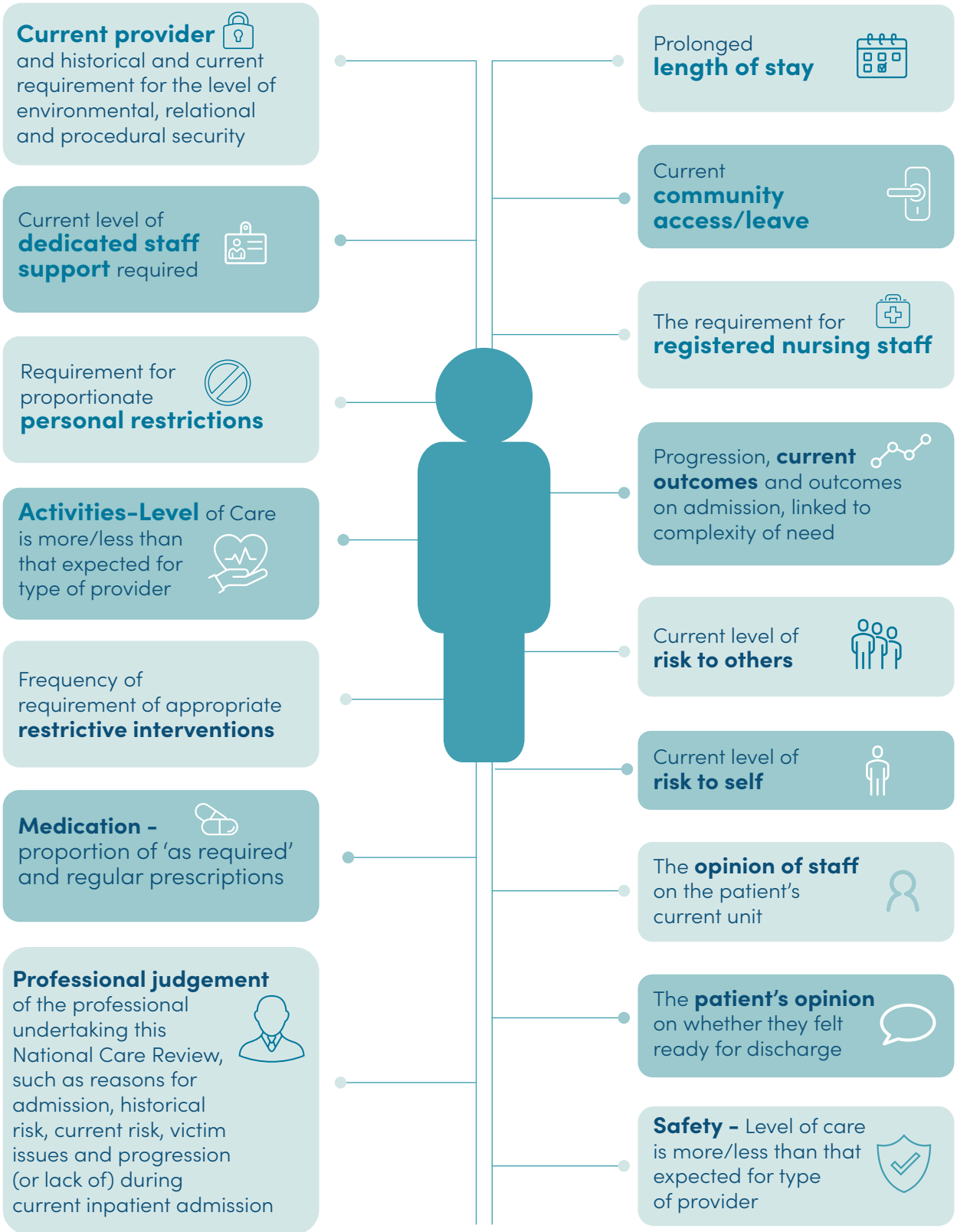
Some providers in Wales have expressed a desire to build new facilities or to expand existing facilities but are unable to do so due to Welsh Government legislation.

This National Care Review considered a range of elements in relation to the patients care regime in order to determine whether a recommendation should be made that the patient be considered for transition to another type of provider or to a community placement. These elements are presented in Figure 128.

This National Care Review has validated every recommendation for transition with senior clinical staff on the unit currently caring for the patient.

Figure 128

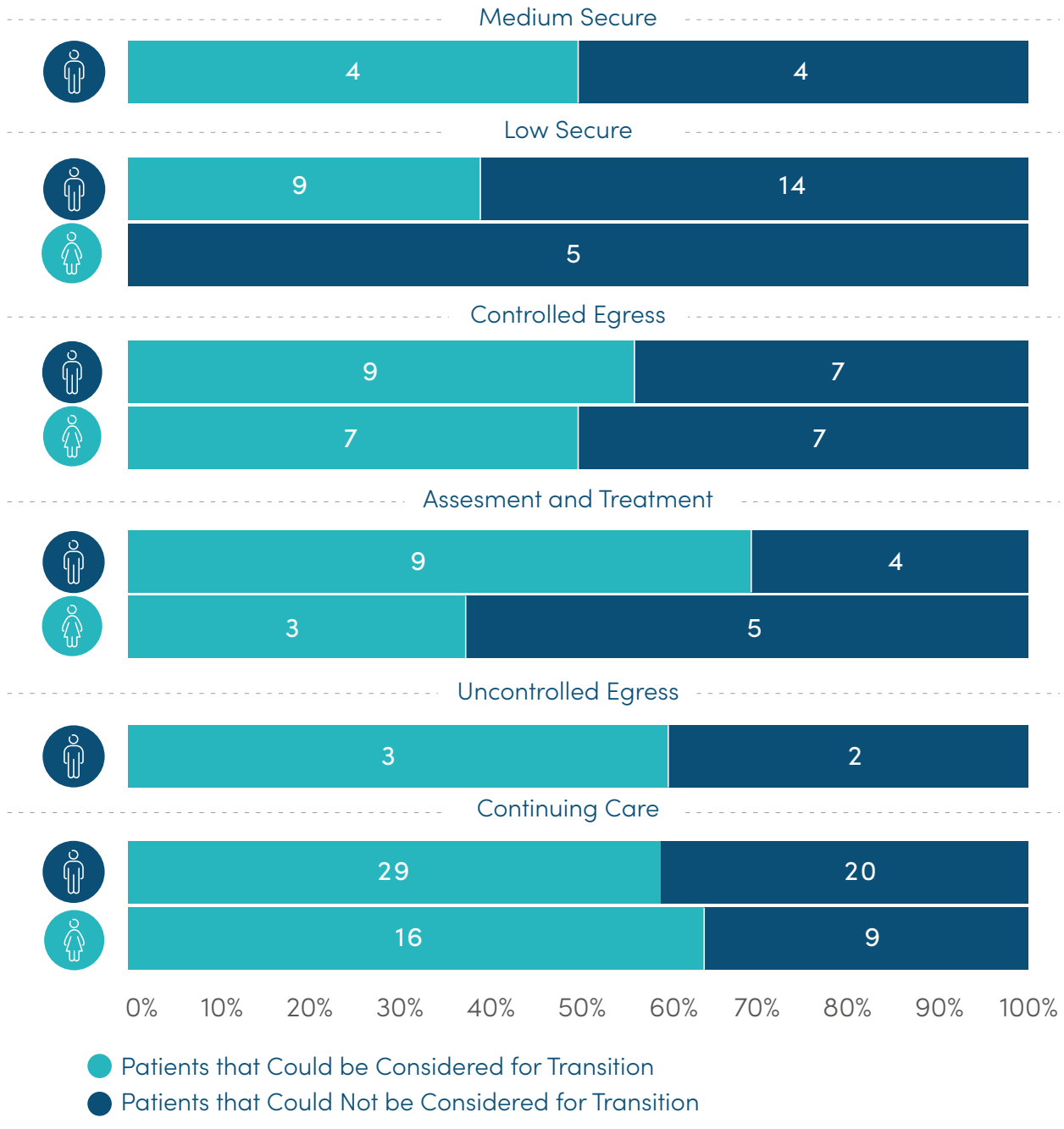
Elements Considered in Respect of the Patients Readiness to Transition



Of the 166 patients forming part of this National Care Review, 77 patients (46%) were considered cared for in an appropriate environment and not ready for transition at that time, although planning for discharge should remain a priority. The remaining 89 patients (54%) could be considered for transition.

Figure 129 presents the number of patients who could be considered for transition, by type of provider and gender. The Figure shows that 63 male patients (55%) and 26 female patients (50%) could be considered for transition.

Figure 129:
Patients that could be Considered for Transition by Type of Provider & Gender



Patients considered ready for transition, by each type of provider, are discussed in Sections 32.1-32.6.

When the costs of new community placements are less than the costs of current provision, resources are able to be reinvested in learning disability services in order to prevent new admissions and to provide enhanced community care.

Costs detailed, in this National Care Review as part of transition are based on the difference between current day cost, as provided by the commissioner, and the new day cost, based on the National Collaborative Framework prices or 'general ledger' data provided by Health Boards.

Where there is a recommendation that a patient be considered for transition to a non-hospital placement, a residential home placement has been indicated and costed as the details for these types of providers were available, although alternatives should be considered if available.

It is preferred, where safe and appropriate, that accommodation models involving housing associations, local authorities and social care providers are arranged for transitioning patients, in line with Welsh Government policy.[228]

Transition can be an unsettling and patients may require dedicated staff support during this time. An additional 6-14 hours per day of dedicated staff support has been included in the estimated cost of transition to a residential home, regardless of whether the patient is currently receiving this dedicated staff support. If less dedicated staff support is required, new costs would be lower and more resources could be reinvested in community services. Conversely, costs would be higher if more dedicated staff support is required.

32.1 Medium Secure

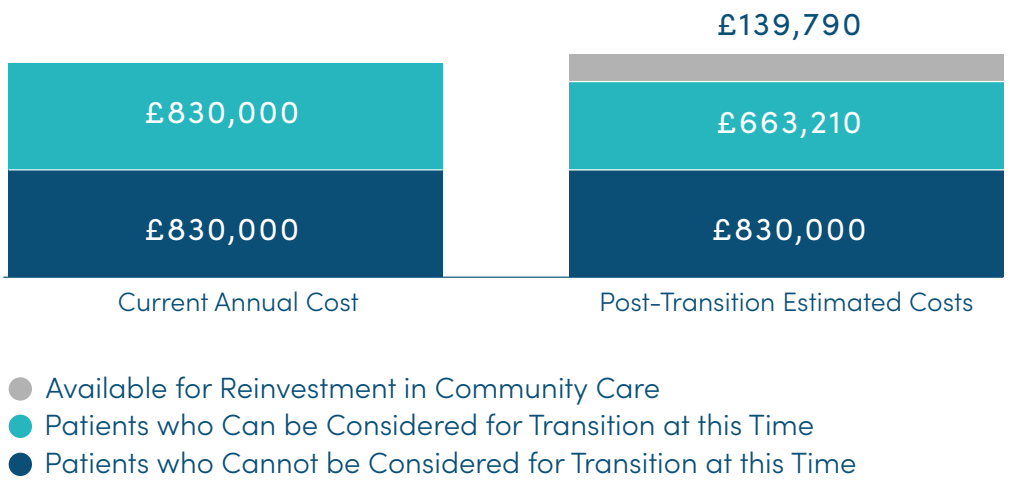
This National Care Review found that, of the 8 male patients cared for in medium secure units:

- 4 male patients (50%) could be considered cared for in an appropriate environment and not for transition at this time.
- 4 male patients (50%) could be considered for transition of which:
  - 3 male patients (38%) could be considered for transition to low secure units.
  - 1 male patient (12%) could be considered for transition to a residential home.

The current cost for these 8 patients in medium secure units was £1,606,000. Figure 130 presents the annual costs for medium secure units and shows that, post-transition, the reduction in costs for the 4 patients recommended for transition would enable a reinvestment in community services of £139,790.

Figure 130:

Costs of Current Medium Secure Provision, Post-Transition Estimated Cost & Reinvestment Opportunity for Community Care



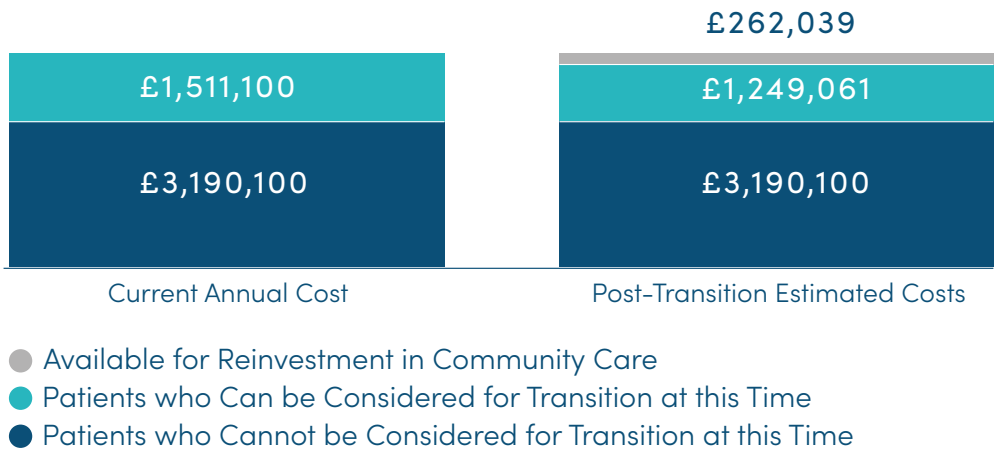
32.2 Low Secure

This National Care Review found that, of the 28 patients cared for in low secure units:

- 14 male patients (50%) could be considered cared for in an appropriate environment and not for transition at this time.
- 5 female patients (18%) could be considered cared for in an appropriate environment and not for transition at this time.
- 9 male patients (32%) could be considered for transition of which:
  - 1 male patient (4%) could be considered for transition to controlled egress units.
  - 2 male patients (7%) could be considered for transition to uncontrolled egress units.
  - 6 male patients (21%) could be considered for transition to residential care services.

The current cost for 28 patients in low secure units was £4,701,200. Figure 131 presents the current annual costs for low secure care and shows that, post-transition, the reduction in costs for the 9 patients would enable a reinvestment in community services of £262,093.

Figure 131:
Costs of Current Low Secure Provision, Post-Transition Estimated Cost & Reinvestment Opportunity for Community Care



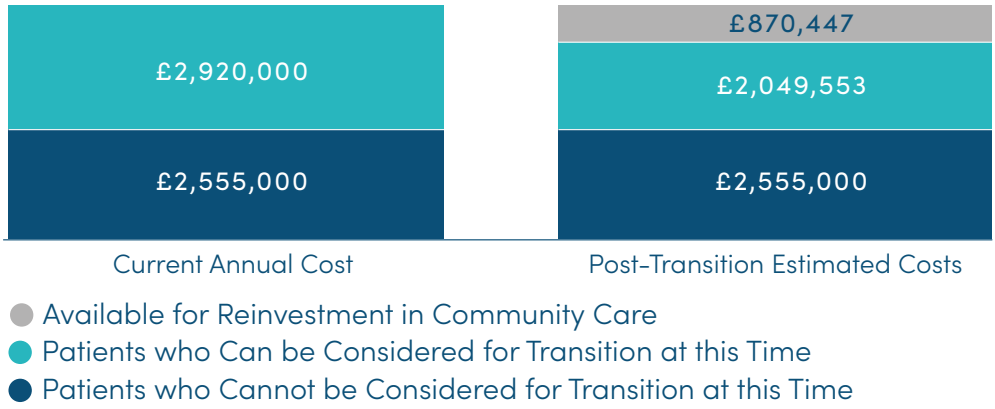
32.3 Controlled Egress

This National Care Review found that, of the 30 patients cared for in controlled egress units:

- 7 male patients (23%) could be considered cared for in an appropriate environment and not for transition at this time.
- 7 female patients (23%) could be considered cared for in an appropriate environment and not for transition at this time.
- 9 male patients (30%) could be considered for transition of which:
  - 1 male patient (3%) could be considered for transition to a low secure unit.
  - 8 male patients (27%) could be considered for transition to a residential care placement.
- 7 female patients (23%) could be considered for transition to a residential care placement.

The current cost for these 30 patients in controlled egress units was £5,475,000. Figure 132 presents the annual costs for controlled egress care and shows that, post-transition, the reduction in costs for the 16 patients recommended for transition would enable a reinvestment in community services of £870,447.

Figure 132:
Costs of Current Low Secure Provision, Post-Transition Estimated Cost & Reinvestment Opportunity for Community Care



32.4 Assessment & Treatment

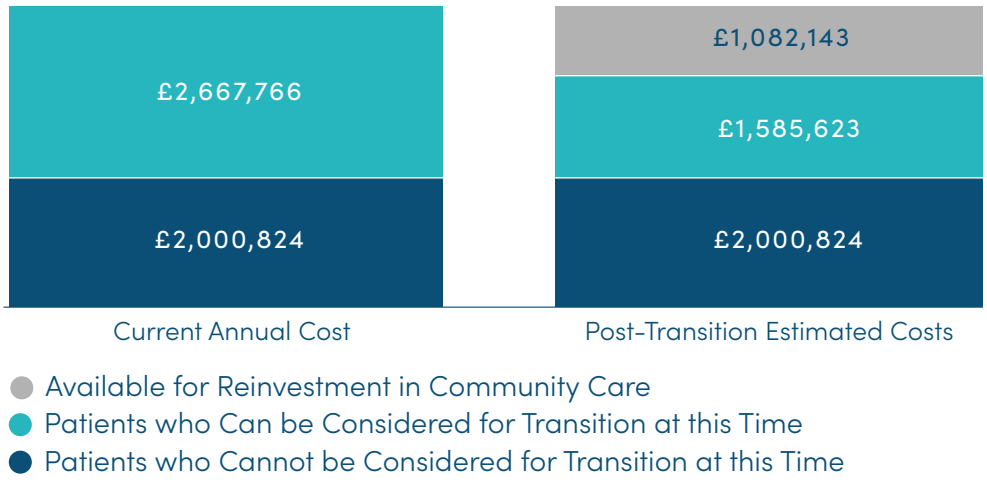
This National Care Review found that, of the 21 patients cared for in assessment and treatment units:

- 4 male patients (19%) could be considered cared for in an appropriate environment and not for transition at this time.
- 5 female patients (24%) could be considered cared for in an appropriate environment and not for transition at this time.
- 9 male patients (43%) could be considered for transition to a residential care placement.
- 3 female patients (14%) could be considered for transition to a residential care placement.

The current cost of these 21 patients in assessment and treatment units was £4,668,590. Figure 133 presents the annual costs for assessment and treatment units and shows that, post-transition, the reduction in costs for the 12 patients recommended for transition would enable a reinvestment in community services of £1,082,143.

Figure 133:

Costs of Current Assessment and Treatment Provision, Post-Transition Estimated Cost & Reinvestment Opportunity for Community Care



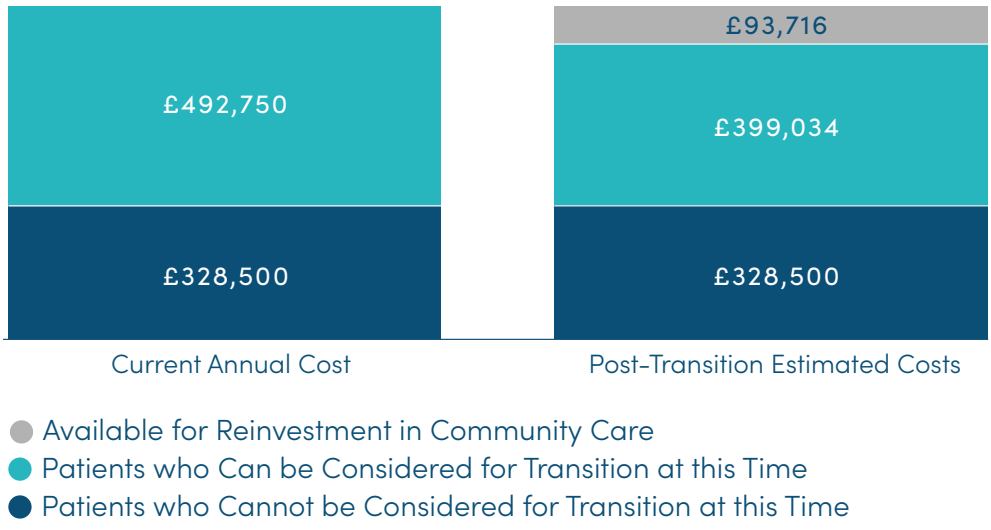
32.5 Uncontrolled Egress

This National Care Review found that, of the five patients cared for in uncontrolled egress units:

- 2 male patients (40%) could be considered to be cared for in an appropriate environment and not for transition *at this time.*
- 3 male patients (60%) could be considered for transition to a residential care placement.

The current cost of these 5 patients in uncontrolled egress units is £4,668,590. Figure 134 presents the annual costs for uncontrolled egress care and shows that, post-transition, the reduction in costs for the 3 patients recommended for transition would enable a reinvestment in community services of £93,716.

Figure 134:
Costs of Current Uncontrolled Egress Provision, Post-Transition Estimated Cost & Reinvestment Opportunity for Community Care



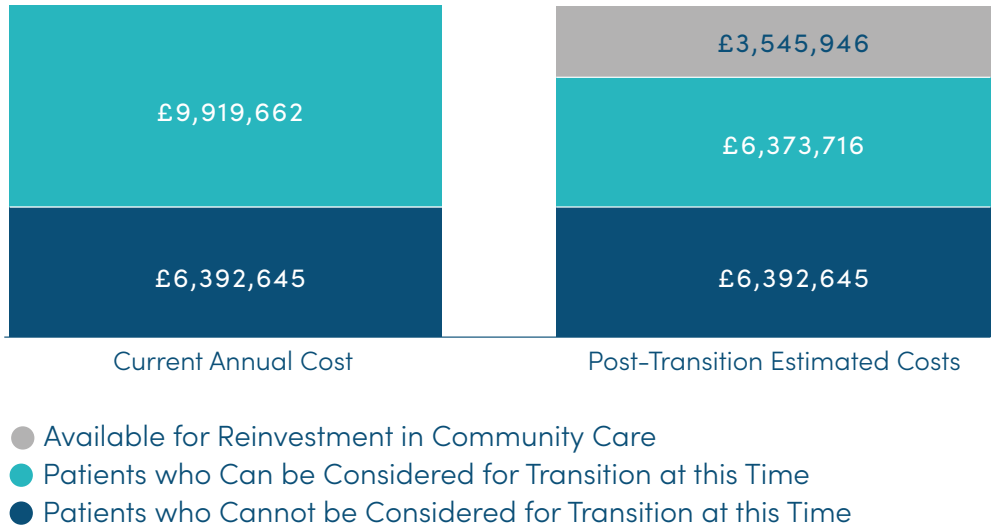
32.6 Continuing Care

This National Care Review found that, of the 74 patients cared for in continuing care units:

- 20 male patients (27%) could be considered to be cared for in an appropriate environment and not for transition at this time.
- 9 female patients (12%) could be considered to be cared for in an appropriate environment and not for transition at this time.
- 29 male patients (39%) could be considered for transition to a residential home.
- 16 female patients (22%) could be considered for transition to a residential home.

The current cost of these 74 patients in continuing care units is £16,312,266. Figure 135 presents the annual costs for continuing care and shows that, post-transition, the reduction in costs for the 45 patients recommended for transition would enable a reinvestment in community services of £3,545,946.

Figure 135:
Costs of Current Continuing Care Provision, Post-Transition Estimated Cost & Reinvestment Opportunity for in Community Care



32.7 Transition

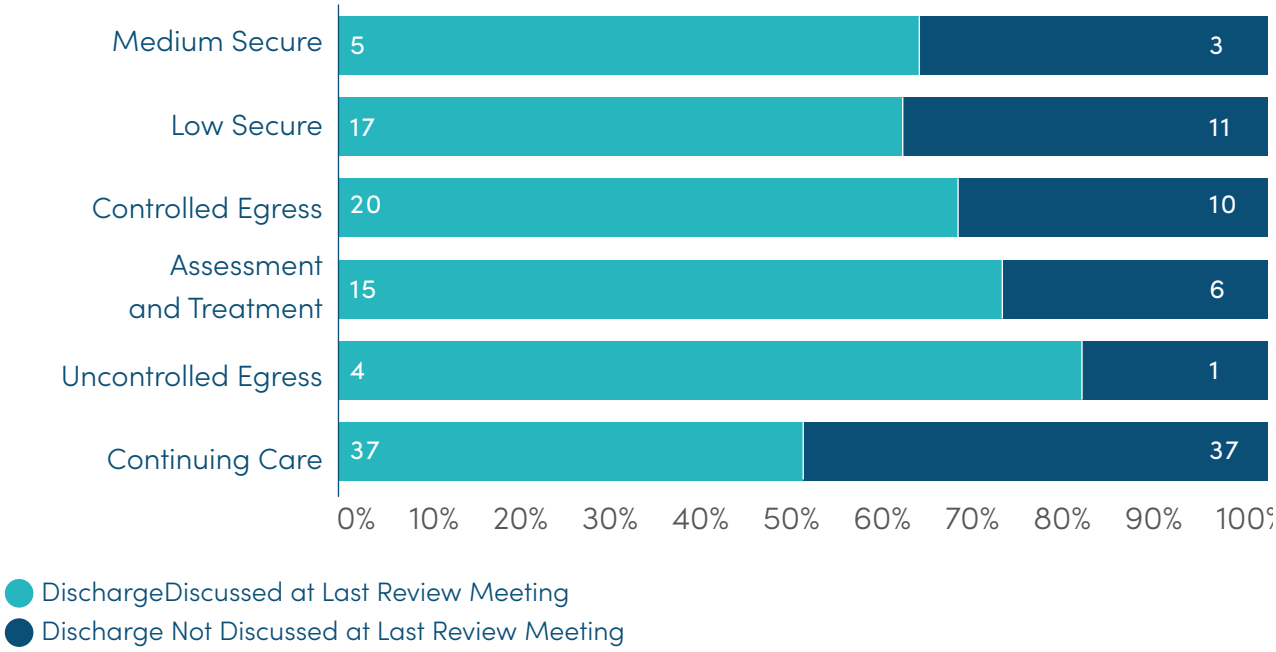
Planning for transition should start from the point of admission[229] and patients should be supported to be discharged as soon as possible.[230] Patients being discharged from hospital are entitled to expect and receive a smooth transition from one stage of care to the next.[231] Discharge planning should involve the patient and their families at every stage.

Transition planning is about arranging the next steps in the patient's care journey, whether that is to another hospital or to the community, and agreeing what support will be in place. It is recommended to discuss the patient's plans for transition at the regular care planning meeting and to invite local community team representation.[232]

This National Care Review found that 98 patients (59%) had their transition discussed at the last care planning meeting, attended by their local community team.

Figure 136 presents the number of patients who had transition discussed at the latest care planning meeting, by each type of provider.

Figure 136:
Patients Transition Discussed at Latest Care Planning Meeting by Type of Provider

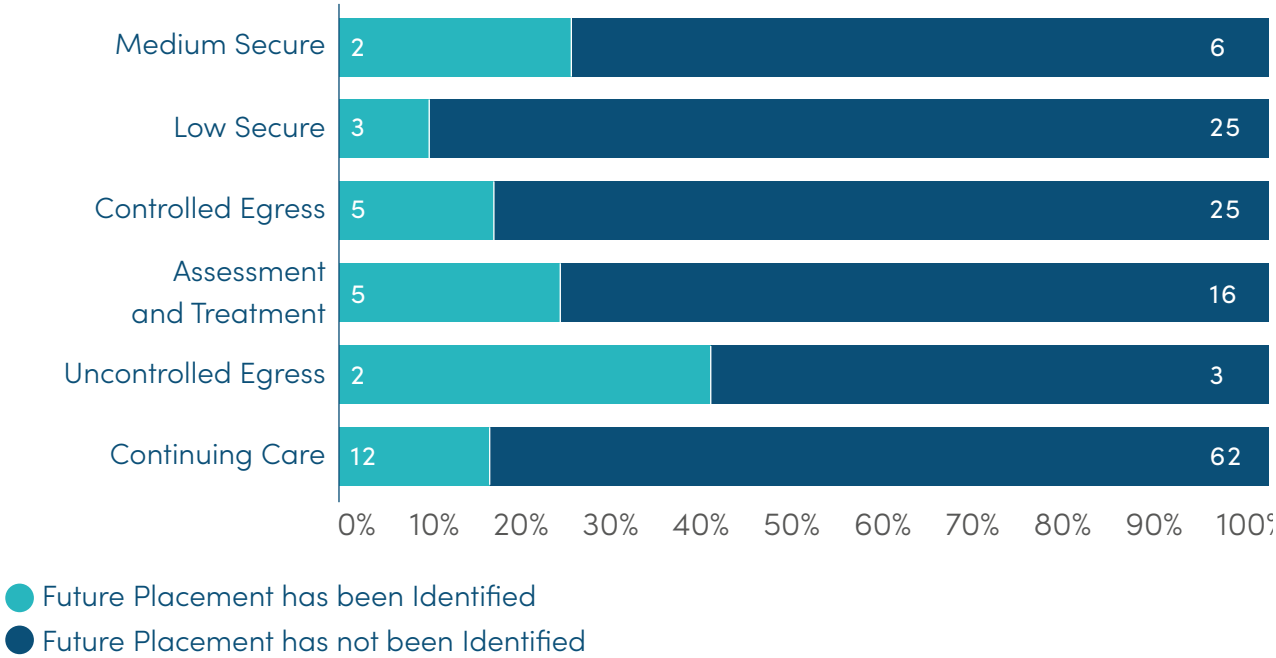


An indicator that transition planning is significantly progressed, is when the future placement has been identified and community support has been arranged. This National Care Review found that 29 patients (17%) had a future placement identified and 137 patients (82%) did not.

Figure 137 presents the number of patients who had a future placement identified within their care plan, by each type of provider.

Figure 137:

Patients With Future Placement Identified, By Type Of Provider



There should be a regular review of discharge planning on units, and services should provide '*clear rationale*' if discharge does not occur in a timely manner.[233]

Commissioners must ensure continuity and stability in service delivery during transition. In order to support continuity of care, consideration should be given to transferring hospital staff to work in the new community services.[234]

Commissioners should aim to redirect resources from relatively expensive inpatient and out-of-area care to provision of care locally in the community. Although there may be '*initial costs*' to set up care facilities outside of hospitals, studies suggest that there will be '*decreased spending*' on '*expensive*' inpatient care and improvements in quality of life for the individual.[235]

This National Care Review found that if patients who could be transitioned were transitioned, there would be significant resources available for reinvestment in learning disability community services, which in turn could prevent future admissions.

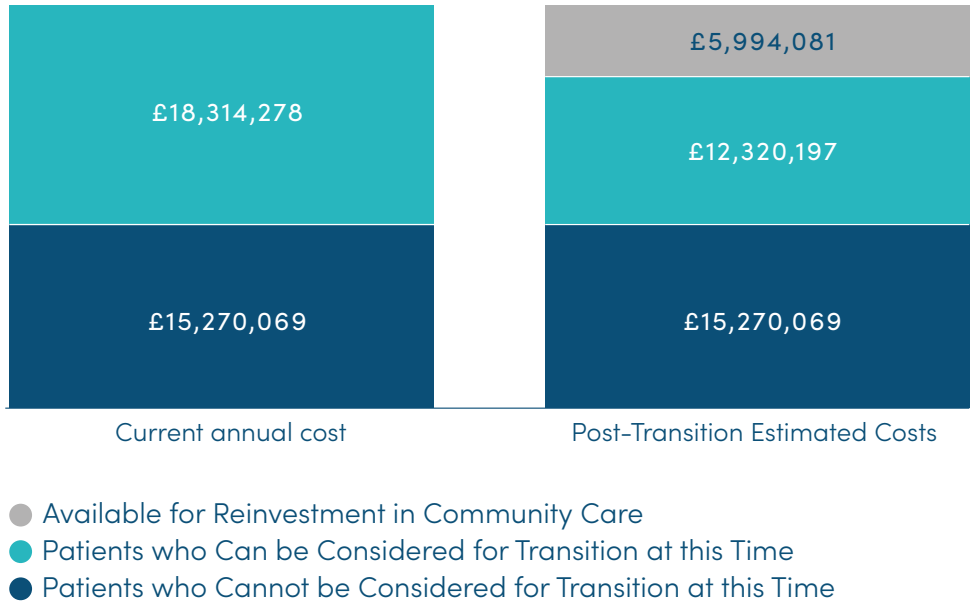
A recent report has stated that '*too many*' patients with a learning disability are in hospital because of a lack of local, intensive community services.[236]

The Welsh Government has recommended that resources be put into community learning disability services.[237] Studies have found that, should funding be available, social investment and the 'third sector' could support the development of enhanced community services.[238]

Figure 138 presents the annual costs of care for all patients and the estimated costs if all 89 patients who could be transitioned were transitioned. The Figure shows that 18% of the current costs (£5.994 million) could be available for reinvestment into community services.

Figure 138:

Current Costs, Post-Transition Estimated Cost & Reinvestment Opportunity for Community Services



Studies suggests that a move to the community is linked to an improved quality of life for individuals with learning disabilities.[239] Personal accounts also suggest that the move from institutions into the community have brought '*positive changes*' in individual's lives.[240] Studies have found that there was evidence of improvement in personal skills, choice, self-determination, social participation and satisfaction when patients moved from institutions to community settings.[241]

In studies on previous transitions, families have often felt that professionals had given '*insufficient consideration of the psychosocial impact*' which a change of environment would have on patients. Even the most disabled long-stay patients were felt by their relatives to have formed attachments to staff, aspects of the environment or familiar routines.[242] When planning transition, the care team must take account of the impact of the patient having spent a significant amount of their lives with their current provider, and that they may view it as 'home'.

It is an aim of NHS Wales to achieve better outcomes and a better experience for patients, at reduced cost. [243] Several health boards are reducing 'out of area' placements and increasing local capacity. [244]

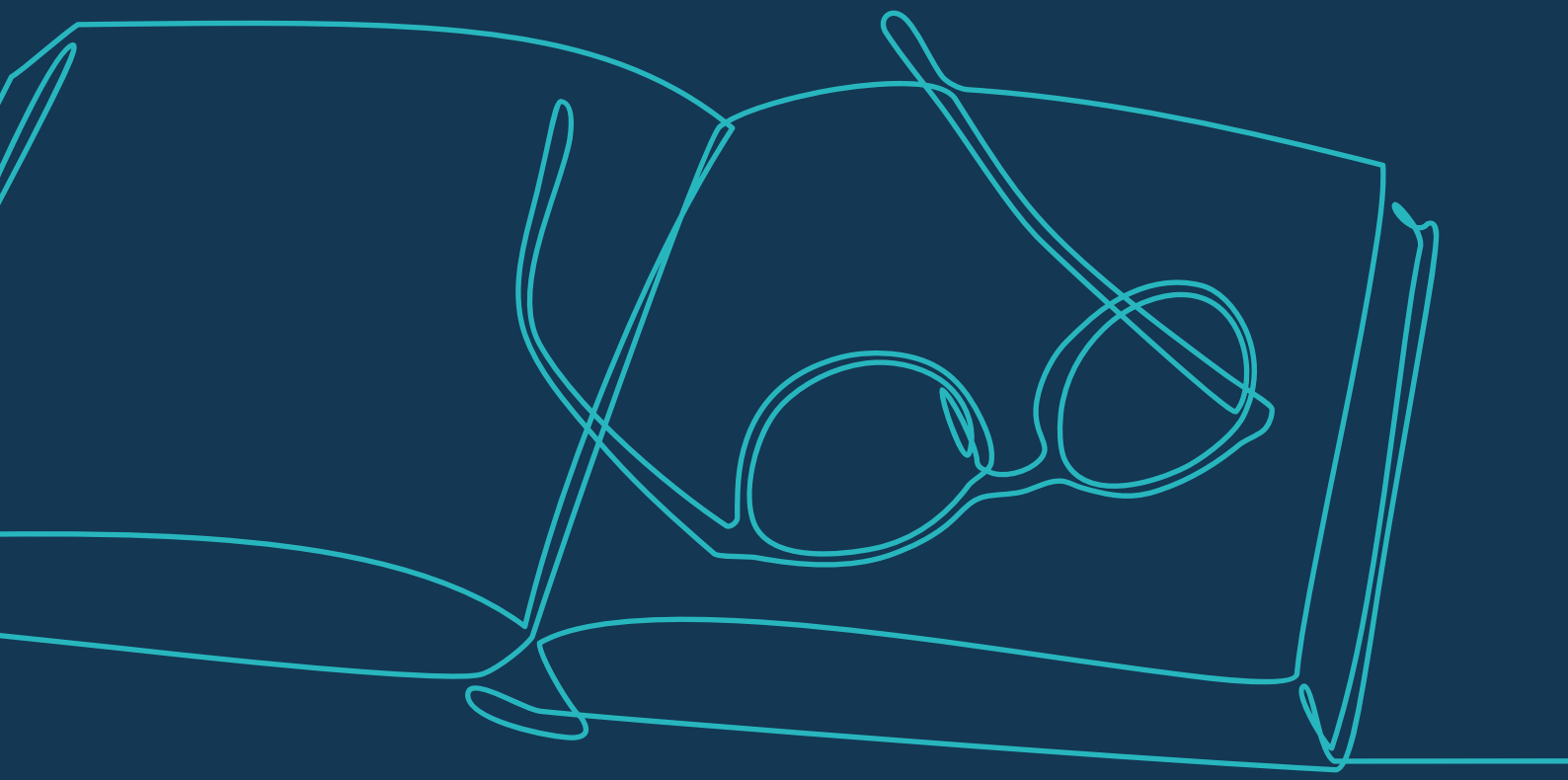
Many Health Boards have transition plans in place for some or all of their patients. The transition process should be tailored to the patient and their family and should focus on the patient and the support that they require to meet their needs, hopes, aspirations and outcomes.

Transition needs to be a process that takes place over a period of time, and not a 'one off' event. Its focus should not be on closing beds or reinvesting resources, but on improving the care and lives of patients.

National Care Review Recommendations

63) Commissioners should ensure that all transition plans are enacted.
64) Commissioners should ensure that all patients have a plan in place, identifying the outcomes to be achieved in order to transition to the next step on their care journey.
65) Providers should ensure that patients and their families and carers are involved in developing and enacting the transition plan.
66) Providers should ensure that the transition plan is discussed and progressed by the unit staff and local care team at their regular meetings.
67) Commissioners should have in place a mechanism to review transition plans across the services they commission, to ensure that barriers to progress are removed.
68) Commissioners should consider optimal planning arrangements for new models of enhanced inpatient services at a local, regional and national level.
69) Commissioners should consider investment in early intervention and admission-prevention community services.
70) To support transition and improve community services the Welsh Government should support Regional Partnership Boards to develop a sustainable funding model, including social investment and social enterprise.

PART F
Appendices & Endnotes



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Appendix A

National Care Review Methodology

Each number denotes the corresponding section in Parts A-E of this National Care Review, if number is absent is means methodology is redundant for this section.

1. Introduction

- Diagnostic and Statistical Manual of Mental Disorders V-diagnosis of intellectual developmental disorder-Intellectual disability involves impairments of general mental abilities that impact adaptive functioning in three domains, or areas. These domains determine how well an individual copes with everyday tasks:
  - The conceptual domain includes skills in language, reading, writing, math, reasoning, knowledge, and memory.
  - The social domain refers to empathy, social judgment, interpersonal communication skills, the ability to make and retain friendships, and similar capacities.
  - The practical domain canters on self-management in areas such as personal care, job responsibilities, money management, recreation, and organising school and work tasks.

The disorder is considered chronic and often co-occurs with other mental conditions like depression, attention-deficit/hyperactivity disorder, and an autistic spectrum disorder. DSM-5 emphasises the need to use both clinical assessment and standardised testing of intelligence when diagnosing intellectual disability, with the severity of impairment based on adaptive functioning rather than IQ test scores alone.

- Letter dated read 4 February 2019 from Welsh Government Professor Jean White: Dear colleagues, Re: Review of Welsh Commissioned Learning Disability Independent Hospital.

2. Placements

- As part of our assurance mechanism, to inform strategic thinking and to understand the impact of the NHS England Transforming Care Agenda on Welsh Patients, I have requested the National Collaborative Commissioning Unit: Quality Assurance Improvement Service to undertake a review of persons currently placed within independent learning disability hospitals. These reviews will take place between February and April 2019. The process for these reviews shall be that a clinician from the National Collaborative Commissioning Unit: Quality Assurance Improvement Service shall attend each hospital to complete an 'Individual Progress Review'. This review will identify a broad range of key information including legal

circumstances, support requirements, risk profile, medication management, physical health needs, planned outcomes, activities & leave. Where possible, a clinical recommendation shall be made for the type of ongoing support services required or actions required to enable effective progress to be made. If quality or safety concerns are identified during the review process appropriate action shall be taken including reporting to relevant safeguarding authorities and local commissioning teams. At the end of this national review a report shall be circulated which will identify key themes in relation to the assessed areas outlined above. At the end of the review detailed information relating to each patient shall be provided to the relevant team(s) within each Health Board. I would be grateful for your full support of this important review and if you have any further questions please contact Shane Mills.

Further verbal clarification: all learning disability hospitals not just 'independent learning disability hospitals' were to be within scope.

3. Methodology Overview

- The National Collaborative Commissioning Unit (NCCU) supports the Chief Ambulance Services Commissioner and National Programme for Unscheduled Care as well as undertaking bespoke, local and national commissioning work. The Quality Assurance Improvement Service is an operational arm of the NCCU and undertakes National Care Reviews and other work on behalf of Welsh Government. It also manages the three NHS Wales National Collaborative Mental Health and Learning Disability Frameworks for CAMHS, Hospitals and Care Homes as well as undertaking local and national mental health and learning disability work on behalf of the NHS and local authorities.

4. Types of Provider

- Definitions have been in use by NCCU Quality Assurance Improvement Service for the purposes of commissioning based loosely on Mental Health Network-Defining Mental Health Services published in 2012 and endorsed by the Royal College of Nursing and Care Quality Commission.

- Individual categories were identified as:
  - High Secure.
  - Medium Secure.
  - Low Secure.
  - Controlled Egress alternatively termed 'locked rehabilitation.'
  - Assessment & Treatment alternatively termed 'acute care.'
  - Uncontrolled Egress alternatively termed 'unlocked rehabilitation.'
  - Continuing Health alternatively termed 'residential health services.'

5. Overview of Learning Disability Patients

- Patient numbers from Wales and England correct at time of review.
- National Collaborative Framework For Adult Residents In Care Homes covers residential care.

6. Commissioners

- Responsible commissioners were identified through the National Framework Database or direct consultation with Health Board teams.
- Note that Swansea Bay University Health Board manages some inpatient services on behalf of Cwm Taf Morgannwg & Cardiff and Vale Health Boards.
- Also, commissioning responsibility for some individuals has recently changed due to boundary changes between Swansea Bay and Cwm Taf Morgannwg.

7. Providers

- Providers of services to relevant patients were identified via the NHS Wales National Framework for Adult Mental Health & Adult Learning Disability Hospitals database.

- Further relevant patients who were not placed via the National Collaborative Framework were identified by direct contact with the seven Health Boards.

- High Secure
  - Nottingham Healthcare NHS Foundation Trust - Rampton Hospital, Nottinghamshire.

- Medium Secure
  - Riverside Healthcare – Cheswold Park Hospital, South Yorkshire.
  - Priory Healthcare – Kneesworth House Hospital, Cambridgeshire.
  - Priory Healthcare – St John's House Hospital, Suffolk.
  - Priory Healthcare – Calverton Hill, Nottinghamshire.
  - Merseycare NHS Foundation Trust – Whalley Hospital, Lancashire.
  - St Andrew's Healthcare – Northamptonshire.
  - St Andrew's Healthcare – Nottinghamshire.

- Low Secure
  - Priory Healthcare – Burston House Hospital, Norfolk.
  - Priory Healthcare – St John's House Hospital, Suffolk.
  - Priory Healthcare – Llanarth Court Hospital, Monmouthshire.
  - Merseycare NHS Foundation Trust – Whalley Hospital.
  - St Andrew's Healthcare – Northamptonshire.
  - St Andrew's Healthcare – Nottinghamshire.
  - Elysium Healthcare – Cefn Carnau, Caerphilly.

- Controlled Egress
  - ASC - Breitmet Hospital, Lancashire.
  - Priory Healthcare – Church Village Hospital, Rhondda Cynon Taf.
  - The Huntercombe Group – Eldertree Lodge, Shropshire.
  - Elysium Healthcare – St Mary's Hospital, Cheshire.
  - Elysium Healthcare – The Woodhouse Hospital, Staffordshire.
  - Ludlow Street Healthcare – Pinetree Court Hospital, Cardiff.

- Uncontrolled Egress
  - Priory Healthcare – Church Village Hospital, Rhondda Cynon Taf.
  - Mental Healthcare UK – St David's Hospital, Denbighshire.

- Acute Assessment & Treatment
  - Betsi Cadwaladr ULHB – Mesen Fach, Conwy.
  - Aneurin Bevan LHB – Ty Lafant, Torfaen.
  - Swansea Bay ULHB – LLwyneryr, Swansea.
  - Swansea Bay ULHB – Hafod Y Wennol, Vale of Glamorgan.
  - Swansea Bay ULHB – Rowan House, Cardiff.

- Continuing Health
  - Betsi Cadwaladr ULHB – Mesen Fach, Conwy.
  - Betsi Cadwaladr ULHB – Tan y Coed, Conwy.
  - Betsi Cadwaladr ULHB – Foelas, Conwy.
  - Aneurin Bevan LHB – Mitchell Close, Torfaen.
  - Aneurin Bevan LHB – Twyn Glas, Caerphilly.
  - Swansea Bay ULHB – Dan y Deri, Swansea.
  - Swansea Bay ULHB – Bryn Afon, Rhondda Cynon Taf.
  - Swansea Bay ULHB – Meadow Court, Rhondda Cynon Taf.
  - Swansea Bay ULHB – Swn Yr Afon, Neath Port Talbot.
  - Swansea Bay ULHB – Dan Y Bont, Bridgend.
  - Swansea Bay ULHB – Ty Garth Newydd, Rhondda Cynon Taf.
  - Swansea Bay ULHB – Llety Newydd, Cardiff.
  - Swansea Bay ULHB – Laurels & Briary, Cardiff.
  - Hywel Dda LHB – Ty Bryn, Carmarthenshire.
  - Hywel Dda LHB – Bro Myrddyn, Carmarthenshire.
  - Hywel Dda LHB – Begelly, Pembrokeshire.
  - Hywel Dda LHB – Greville Court, Pembrokeshire.

8. Service Change

- Aneurin Bevan University Health Boards 'In One Place' project is a Special Purpose Vehicle that facilitates a collaborative approach to dealing with the accommodation needs of people with complex health and social care need.
- Swansea bays University Health Board (formally Abertawe Bro Morgannwg University Health Board) 'Closer to Home' project is a partnership with the health board with Swansea, Neath and Bridgend local authorities plus First Choice and Gwalia to develop local services for people with complex health needs and challenging behaviours.
- Other Health Boards or Local Authorities may have other similar projects in place.

9. Patient Gender

- Male, Female or other was identified via clinical documentation at site.

10. Age

- Patient age was identified via clinical documentation at site.

11. Diagnosis

- Patient diagnosis related to the formal clinical diagnosis as identified within clinical documentation.
- Individual's Primary secondary and tertiary diagnoses were identified within clinical documentation.
- Diagnoses were identified within the 4 categories:
  - Learning disability.
  - Mental Health.
  - Autistic Spectrum Disorder/Autistic Spectrum Condition.
  - Dementia.

12. Admission Pathway

- The previous placement or patient status prior to the current admission was identified from clinical documentation or discussion with the provider care team.

13. Length of Stay

- Length of stay was calculated from the date of admission recorded within the clinical record.

14. Legal Status

- Individual patient's legal status in line with the Mental Health Act or Mental Capacity Act was identified from clinical records.
- Where relevant, the section of the Mental Health Act the patient was detained under was identified from the clinical record.
- Where relevant, the individual's status in relation to the 'Deprivation of Liberty Safeguards' was identified from the clinical record.

15. Care Coordinator

- The designation of each patient's Care co-ordinator was identified from the provider's clinical records or discussion with the provider care team.

16.1. Care & Treatment Plan

- Individual patient status as a relevant patient under the Mental Health (Wales) Measure 2010 was identified from the clinical records.
- The presence of a current 'Care & Treatment Plan' as defined under the MH(W)M was identified from clinical records.

16.2. Hospital Support Plan

- Provider clinical records were reviewed to verify that:
  - An individual care and support plan was in place.
  - The individual care and support plan addressed all identified needs.
  - Clear and measurable goals and actions to address identified needs.
  - It was evidenced that care and support plans were developed in collaboration with the individual patient.
  - The was a documented review of care and treatment plans.

17. Outcomes

- Individual outcomes relating to 7 defined categories were identified from the clinical record.
- Wording of outcome as written in the patients individual plan may not of always matched the wording of the seven outcomes so 'best fit' outcome was identified .

17.8. Meeting Patient Outcomes

- Outcomes were judged to be either:
  - Present on admission and not currently met.
  - Not identified as an outcome on admission but was an outcome at time of review.
  - An outcome previously identified but met to a degree when need can be met within a lower level of care.

18. Medication

- Individual prescribed medication was identified from the clinical record. Psychotropic medication was identified within 5 broad categories.
- Clinical and medication administration records were reviewed to determine:
  - The number of each type of medication prescribed for each individual.
  - The use and frequency of as required medication for each individual.
  - The use of medication administered via 'Intra-muscular injection' for each individual.

18.6. Reducing the use of Psychotropic Medication

- Clinical and medication administration records were reviewed to determine the completion of a medication review by the prescribing psychiatrist or GP.

19. Medication Side Effects Monitoring

- The use of a formal 'psychotropic medication side-effects monitoring tool' was identified from clinical records and discussion with clinical staff.
- Further clinical monitoring through required blood tests and ECG were also identified from clinical records and discussion with clinical staff.

20. Behaviours that Challenge

- The intensity and frequency of behaviours which challenge or present a risk to themselves or others were identified through review of clinical records.

20.12. Reducing Behaviours Which Challenge

- Cross referenced each patients length of stay in bed days with history of behaviours which challenges.

21. Restrictive Interventions

- The frequency of use of restrictive interventions in response to challenging behaviours was identified through review of clinical records.

22. Reducing Restrictive Interventions/Chemical Restraint

- Data relating to recorded challenging behaviours, restrictive interventions and psychotropic medication was cross referenced and compared.

23. Personal and Blanket Restrictions

- Restrictions relevant to individual patients were identified as referenced within care and treatment plans and legal documentation, i.e. Deprivation of Liberty Safeguards.
- The review also identified areas of 'unit wide' or 'blanket' restrictions, through review of unit policies and protocols as well as discussion with staff and patients.

24. Dedicated Staff Support

- Dedicated individual additional support or supportive observations was identified through clinical records and discussion with clinical staff.

25. Community Access

- Authorised Leave from hospital or planned community access was identified for each individual through review if clinical records. Information was identified relating to frequency and type of Leave or community access available and accessed.

26. Physical Health

- Arrangements to support individual's physical health needs were identified through review of hospital policies and procedures, discussion with clinical staff and review of clinical records.

27. Costs

- Inpatient Services Provider Costing Methodology for Continuing Care and Assessment and Treatment Units was requested for the full year 2018/19 from Swansea Bay, Aneurin Bevan, Hywel Dda and Betsi Cadwaladr Health Boards for Units as these Health Boards are responsible for the delivery of inpatient Services in NHS Wales. The costing information was extracted from the general ledger and included the direct costs for the provision of care and also an allocated overhead cost. A daily cost per patient was calculated from the costing data provided and a weighted average calculation was undertaken in order to calculate an average daily rate for the provision of inpatient services across Wales for Continuing Care and Assessment and Treatment.
- Costing information for Medium Secure, Low Secure, Controlled Egress and Uncontrolled Egress provision was taken for 2018/19 from the National Hospitals Pricing Database, which is maintained by the National Collaborative Commissioning Unit. Detailed patient level costing information is submitted by independent providers who deliver services under the terms and conditions of the National Collaborative Framework for Adults in Mental Health and Learning Disabilities Hospitals for the National Health Service and Local Authorities in Wales and this information includes the direct costs for the provision of care and an allocated overhead cost. The indicative annual cost of each patient was calculated for each resident placement according to the specific commercial rates of the provider and before a weighted average daily cost per patient was calculated.

27.1. Patient Experience and Satisfaction

- Where possible a discussion was held with each patient during the reviews to complete a brief yes/no questionnaire together with a more open discussion.
- A further more in depth questionnaire was carried out with the support of an independent advocate with a smaller group of patients.

28. Environment of Care

- Information relating to individual hospital services was gained through reviewer observations and the completion of a questionnaire with service managers.

29. Levels of Care

- Data relating to how the care and support needs of individual patients were met was gained through review of clinical records and discussion with clinical staff.

29.3. Safety & Activities Level of Care

- Data relating to individual support needs combining safety and activity was identified to provide an overall level of need. The Level of Care was applied by the auditor to ensure consistency.

30. Staffing

- Information relating to the staffing provision at individual hospital services was gained through reviewer observations and the completion of a questionnaire with service managers.

32. In The Right Place

- Following each individual review the review was able to identify individuals where care needs could be met in a lower level of care. This opinion was reached based upon available clinical records & discussion with members of the provider clinical teams. A further process of verification through consultation with unit managers was carried out to ensure a consensus was reached.
- Data was produced in relation to each type of hospital care provision.

33. Transition

- Potential or actual transition planning was identified through clinical records and discussion with the provider clinical teams.
- Costing Methodology for Packages of Care to be provided after transition: In order to calculate an indicative annual cost of patient placements after transition, we used October 2019 benchmarking data from the National Framework for Mental Health and Learning Disabilities Provider Resident Level Costings Database which was provided by the National Collaborative Commissioning Unit. Detailed patient level costing information is submitted by independent providers who deliver services under the terms and conditions of the National Collaborative Framework for Adults in Mental Health and Learning Disabilities Care Homes and Care Homes with Nursing for the National Health Service and Local Authorities in Wales and this information includes the direct costs for the provision of care and an allocated overhead cost.
- In order to provide an indicative annual cost in line with the clinician's assessment of the patient needs after transition, two types of care package were costed utilising the median benchmark costs for LD provision:
- A high care provision included a core care package cost median benchmark rate which includes the direct cost of provision plus overhead costs with 14 hours per day of dedicated care included for the patient.
- An average care provision included a core care package cost median benchmark rate, which includes the direct cost of provision plus overhead costs with 6 hours per day of dedicated care included for the patient.
- These two types of care package were costed for two types of residential care placements:
  - Care Homes.
  - Care Homes with Nursing.
- A daily average benchmark rate was taken for each resident and annualised in order to enable a comparable cost for post transition arrangements.
- Winterbourne View & Social Investment (2014) examined the funding required to build capacity in the community including the development of an outcomes based payments model to support transition and a social property fund to enable the availability of accommodation for people in the community.

Appendix B

Triangulation of measures

This Appendix is a continuation of Section 22 - Reducing Restrictive Interventions.

In this Appendix there is triangulation of the three measures:

- Behaviours that challenge measure (reported range 0-75).
- Restrictive intervention measure (reported range 0-59).
- Psychotropic medications measure (reported range 0-12).

The measures are triangulation for patient's cared for in the following services:

- Medium Secure.
- Low Secure (see Section 22).
- Controlled Egress.
- Assessment & Treatment.
- Uncontrolled Egress.
- Continuing Care.

Medium Secure

Value of behaviours that challenge measure (reported range 0-75), restrictive intervention measure (reported range 0-59) and psychotropic medications measure (reported range 0-12) Colour coding distinct to each measure.

Patient	Gender	Challenging Behaviour Measure	Restrictive Intervention Measure	Psychotropic Medication Measure
1	Male	50	20	6
2	Male	33	18	4
3	Male	31	20	3
4	Male	29	34	0
5	Male	27	50	4
6	Male	19	8	6
7	Male	16	15	3
8	Male	12	13	6

Controlled Egress

Value of behaviours that challenge measure (reported range 0-75), restrictive intervention measure (reported range 0-59) and psychotropic medications measure (reported range 0-12). Colour coding distinct to each measure.

Patient	Gender	Challenging Behaviour Measure	Restrictive Intervention Measure	Psychotropic Medication Measure
1	Male	66	55	7
2	Male	53	27	7
3	Male	28	8	7
4	Male	28	32	7
5	Male	24	27	7
6	Male	22	28	5
7	Male	22	12	2
8	Male	17	13	5
9	Male	17	29	11
10	Male	17	10	3
11	Male	11	5	5
12	Male	10	0	2
13	Male	8	20	3
14	Male	6	0	6
15	Male	4	19	2
16	Male	2	0	4
17	Female	48	16	6
18	Female	48	17	8
19	Female	43	11	9
20	Female	39	9	7
21	Female	25	17	7
22	Female	24	4	7
23	Female	23	20	7
24	Female	22	23	8
25	Female	19	14	7
26	Female	18	0	6
27	Female	18	3	6
28	Female	16	14	3
29	Female	15	9	8
30	Female	13	4	1

Assessment & Treatment

Value of behaviours that challenge measure (reported range 0-75), restrictive intervention measure (reported range 0-59) and psychotropic medications measure (reported range 0-12). Colour coding distinct to each measure.

Patient	Gender	Challenging Behaviour Measure	Restrictive Intervention Measure	Psychotropic Medication Measure
1	Male	75	25	6
2	Male	55	42	8
3	Male	49	17	5
4	Male	39	1	6
5	Male	36	18	6
6	Male	35	0	7
7	Male	33	10	10
8	Male	31	4	1
9	Male	32	18	2
10	Male	28	27	8
11	Male	21	8	7
12	Male	16	0	7
13	Male	6	0	2
14	Female	44	55	7
15	Female	42	12	6
16	Female	23	3	7
17	Female	19	9	6
18	Female	10	0	5
19	Female	9	0	6
20	Female	8	6	4
21	Female	0	0	4

Uncontrolled Egress

Value of behaviours that challenge measure (reported range 0-75), restrictive intervention measure (reported range 0-59) and psychotropic medications measure (reported range 0-12) Colour coding distinct to each measure.

Patient	Gender	Challenging Behaviour Measure	Restrictive Intervention Measure	Psychotropic Medication Measure
1	Male	24	14	8
2	Male	21	20	4
3	Male	19	4	6
4	Male	18	0	6
5	Male	10	16	7

Controlled Egress

Value of behaviours that challenge measure (reported range 0-75), restrictive intervention measure (reported range 0-59) and psychotropic medications measure (reported range 0-12) Colour coding distinct to each measure.

Patient	Gender	Challenging Behaviour Measure	Restrictive Intervention Measure	Psychotropic Medication Measure
1	Male	58	30	6
2	Male	54	34	1
3	Male	53	17	12
4	Male	53	29	5
5	Male	49	5	7
6	Male	47	10	4
7	Male	36	2	4
8	Male	36	0	6
9	Male	35	14	2
10	Male	32	20	8
11	Male	30	10	5
12	Male	30	12	6
13	Male	29	2	4
14	Male	28	10	7
15	Male	27	21	4
16	Male	26	8	4
17	Male	26	7	6
18	Male	26	0	1
19	Male	25	17	7
20	Male	24	15	2
21	Male	22	3	3
22	Male	21	15	2
23	Male	21	9	10
24	Male	20	10	4
25	Male	19	0	2
26	Male	17	6	3
27	Male	17	0	7
28	Male	16	23	4
29	Male	14	3	8

30	Male	14	21	0
31	Male	12	0	1
32	Male	11	21	2
33	Male	11	0	5
34	Male	10	0	4
35	Male	9	32	7
36	Male	9	0	5
37	Male	8	0	3
38	Male	8	1	4
39	Male	7	0	5
40	Male	7	0	4
41	Male	6	0	0
42	Male	4	0	7
43	Male	4	4	3
44	Male	3	0	3
45	Male	1	0	1
46	Male	0	0	0
47	Male	0	0	0
48	Male	0	0	0
49	Male	0	0	5
50	Female	52	32	6
51	Female	51	17	9
52	Female	47	20	4
53	Female	46	1	8
54	Female	42	20	5
55	Female	38	12	11
56	Female	30	5	1
57	Female	29	5	6
58	Female	26	11	1
59	Female	23	0	4
60	Female	20	14	3
61	Female	15	9	0
62	Female	13	16	7
63	Female	10	5	6

64	Female	5	0	7
65	Female	4	1	3
66	Female	2	0	0
67	Female	2	0	0
68	Female	1	0	6
69	Female	1	0	6
70	Female	0	0	0
71	Female	0	0	0
72	Female	0	0	1
73	Female	0	0	0
74	Female	0	0	2

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