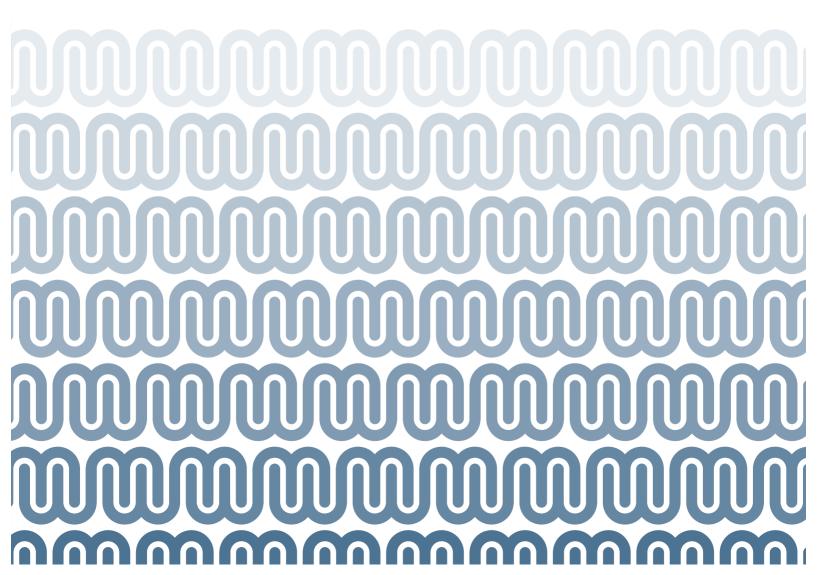


Out of NHS area placements

Themed report

September 2023



Our mission and purpose

Our Mission

To be a leading and independent voice in promoting a society where people with mental illness, learning disabilities, dementia and related conditions are treated fairly, have their rights respected, and have appropriate support to live the life of their choice.

Our Purpose

We protect and promote the human rights of people with mental illness, learning disabilities, dementia and related conditions.

Our Priorities

To achieve our mission and purpose over the next three years we have identified four strategic priorities.

- To challenge and to promote change
- Focus on the most vulnerable
- Increase our impact (in the work that we do)
- Improve our efficiency and effectiveness

Our Activity

- Influencing and empowering
- Visiting individuals
- Monitoring the law
- Investigations and casework
- Information and advice

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Foreword - Julie Paterson, chief executive



When we need care and treatment, most of us are admitted to an NHS hospital or facility close to home, and close to our local communities. However, for some people who have highly complex, specialist needs that cannot be met locally, care and treatment may need to be provided out with their NHS health board area.

For this report, we wanted to examine out of area placements for people with mental ill health or learning disability.

We focused on 59 of the 162 individuals from Scotland who are in this category, most of whom are cared for in private sector facilities in Scotland and for some, in England. We heard from them directly wherever possible, and from their relatives, and learned about their experience of referral, about their care and treatment, and about any plans for their return to their home area.

We also sought to assess the impact and cost of out of area placements.

We were glad to hear that the majority of individuals who could tell us about their out of area placement were positive about their care and treatment, as were their relatives. But we also heard how individuals and families were unsure of plans for a return to their home area. We heard about the impact on relatives of travelling to see their family member, and the toll that this took on their relationship.

Indeed, the average length of stay for the majority of those individuals whose care we reviewed in an out of area placement was eight years. One person had been out of area for 28 years.

We also found discharge planning to be a concern for both the current service providers and for the health boards who made the referrals. For the current providers, they identified that getting engagement from the funding health board could be challenging and slow; for the funding service, it was around their concerns relating to a lack of an appropriate local service, and the risk of relapse for the individual.

Funding

Our very conservative estimate is that over £13 million a year is being spent by Scottish NHS services on out of area private care and treatment for the 59 people we saw. We expect the figure to be higher in actual costing, and considerably higher for the total 162 people we identified as out of area.

We had difficulty in getting accurate information on costing and on who had an oversight of placements once an individual had moved out of the local NHS area. Amongst our seven recommendations – two to health boards and five to Scottish Government – we include one asking Scottish Government to review the monitoring of the funding costs for out of area placements and sit this with a national organisation such as NHS National Service Scotland, through the National Services Division, for better oversight and scrutiny.

There is clearly an opportunity to take a national strategic approach to out of area placements and use this significant funding to develop and create innovative local solutions to the care and treatment of those people with the most complex needs.

Introduction

The Commission undertakes national themed visits that report on the care and treatment of particular groups of people across Scotland; this enables us to compare the different approaches taken in response to identified needs.

In 2023, we undertook a themed visit to people whose care was being provided out with their local NHS Scotland health board area, in both Scotland and England. We wanted to hear about people's experience of being referred to a service that was different to that of their local health provider; how they viewed their care before and after they moved, and what they thought would have made a difference had the care they needed been provided nearer to their own home. Where family/carers were actively involved, we were able to gather their views on their involvement in the transfer process and the impact that this had had on them too.

We also wanted to get more information from the services providing out of area care and to hear from the NHS services that were funding external placements. We wanted to know who was involved, what they offered and how this was reviewed, and we also wanted to try to get an estimate of the cost of the out of area care and treatment.

Background

Publications, policies and guidance

In recent years, there has been an increasing focus on the impact and cost of having the care and treatment of NHS patients in Scotland take place out with their local health board area. These people are likely to have complex, specialist needs, and the care and treatment they need is likely not to be provided by their own NHS health board's facilities.

For this group of individuals, who either have a main diagnosis of a mental health condition, learning disability or addiction, their care is funded by their NHS board in Scotland, but they are treated either by the NHS, but not in Scotland (e.g. by NHS England) or out with the NHS (e.g. in a private/voluntary sector/local authority care home or private hospital).

When this occurs, guidance published by Scottish Government¹ has set out the responsibilities for the commissioning of an individual's care by the NHS.

In 2018, a report published by Scottish Government found that some people with learning disabilities and complex needs were living far from home; it identified that there was an urgent need to address this issue. The report titled *Coming Home*² highlighted the challenge of finding appropriate and sustainable community placements that could support people with learning disabilities and complex needs. There were numerous examples where individuals had had multiple placement breakdowns, hospital admissions and difficult experiences having not received the right support at the right time from their local NHS services.

In NHS England, the landscape of inpatient NHS healthcare for people with learning disabilities and/or autistic spectrum disorder has now gone from one that was dominated by NHS provision to one in which the independent sector is now playing the greater role. The Centre for Disability Research³ (CeDR) noted that the average cost for a person who has been in hospital for five years in an independent sector organisation can generate an income of £950,000 although significantly higher levels of income are possible.

In 2020, the *In sight and in mind* report ⁴ looked at the provision of rehabilitation services and found that the impact of a decline in NHS services in NHS England had led to the gap being filled by the private sector. The report pointed out that without adequate local services, there was likely to be an increase in out of area care. Produced by Rethink Mental Illness and the Royal College of Psychiatrists, *In sight and in mind* highlighted that:

"Recent data has shown that, as well as being widespread, out-of-area placements have longer admissions that lead to far higher average costs per stay."

More recently, the draft mental health bill (United Kingdom (UK) Parliament joint committee, 2022) that arose from the 2018 independent review of the Mental Health Act 1983 (England and Wales), chaired by Professor Sir Simon Wessely, made important changes that introduced more choice, accountability, and in the oversight of the use of the mental health act in England and Wales⁵. While there are similarities with some proposals defined in Scotland's Mental

¹ https://www.sehd.scot.nhs.uk/mels/CEL2013_06.pdf

² Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs (www.gov.scot)

³ A-Trade-in-People-CeDR-2017-1.pdf (lancs.ac.uk)

⁴https://www.rethink.org/media/3571/insightandinmind_rehabreport_rethinkmentalillness_rcpsych_february-2020.pdf

⁵ Draft Mental Health Bill 2022 (parliament.uk)

Health Law Review (SMHLR) (Scott, 2022)⁶, the UK parliament's draft bill has usefully identified specific recommendations for individuals whose care is being provided in a private/independent hospital, and not in their local NHS facility. These proposals included:

- Statutory care and treatment reviews by the responsible commissioner where recommendations in the report from the review's report expect integrated care boards and local authorities must "follow" or provide a "good reason" for not following recommendations.
- A review timescale of six months.
- Advocacy that would work across geographical and legal boundaries and could provide an independent service to private and independent hospitals.
- Better regulation of private/independent healthcare providers with regards to discharge planning for the individual.

With the Scottish Government's initial response to the SMHLR delivered in June 2023, there are opportunities to place greater emphasis on reviewing the care and treatment for this group of individuals who are placed out with their local NHS services. Furthermore, and in keeping with the proposals for the Mental Health Act for England and Wales, Scotland could take steps to improve the commissioning of services that could be developed locally and that would meet the needs of this group.

Scottish Government Inpatient Census⁷

In Scotland, data relating to individuals who have a mental health or learning disability diagnosis, and whose care has been provided out with their own local NHS board area is collected and published by Scottish Government.

In December 2022, the Scottish Government published the results of the sixth Mental Health & Learning Disability Inpatient Bed Census and the Mental Health, Addiction and Learning Disability Patients: Out of NHS Scotland Placements Census.

The census had three parts:

- part 1: Mental Health and Learning Disability Inpatient Bed Census
- part 2: Out of NHS Scotland Placements
- part 3: Hospital Based Complex Clinical Care and Long Stay

Parts 1 and 2 were carried out for the first time in October 2014, and repeated again each March from 2016 to present. In March 2016, the census was expanded to include a section on patients receiving hospital based complex clinical care (HBCCC) and long stay patients. The census was paused in 2020 and 2021 due to COVID-19. The 2022 Mental Health Inpatient Census was carried out as at 23:59 on the 11 April 2022 by NHS health boards across Scotland.

The census is designed to provide an understanding of those patients receiving care and treatment in mental health, addiction and learning disability services who are funded by NHS Scotland at a point in time - and for what reason. The census also enhances the Scotlish

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⁶ https://mentalhealthlawreview.scot

⁷ https://www.gov.scot/binaries/content/documents/govscot/publications/statistics/2022/12/inpatient-census-2022-part-1-mental-health-learning-disability-inpatient-bed-census-part-2-out-scotland-nhs-placements/documents/inpatient-census-2022/inpatient-census-2022/govscot%3Adocument/inpatient-census-2022.pdf

Government and NHS Scotland's understanding of mental health, addiction and learning disability services more generally and those using these services. The analytical evidence is intended to inform policy development and service planning, both nationally and locally.

The overall number of patients receiving treatment from mental health and learning disability services funded by NHS Scotland at the 2022 Census was 2,876 inpatients; this was a 13% decrease compared with the 2019 Census and a 26% decrease since the first Census in 2014.

The 2022 census received information from NHS health boards that there were **162** patients treated out with NHS Scotland. Although this number is less than 6% of the total inpatients, the number of patients has increased since the original census (n=146).

Table 1

| | 2014 | 2016 | 2017 | 2018 | 2019 | 2022 |
|----------------|------|------|------|------|------|------|
| All NHS boards | 143 | 137 | 109 | 197 | 126 | 162 |

Those individuals who are treated out with NHS Scotland facilities are likely to have highly complex, specialist needs. Because of the variation in need for individuals, it is said to be more cost effective to send patients out with their own NHS Scotland facilities rather than create dedicated facilities in NHS Scotland. Each care package requires to be considered by the commissioners in the local health board based on the unique needs of the individual.

While funding and scrutiny of the care and treatment of patients who are out with the home board area is the responsibility of that specific NHS health board, for a number of patients, funding can be applied for through the NHS National Services Division, (NSD), part of the National Services Scotland (NSS).

NHS NSD funding

The role of NSD in regard to out of area placements is specific and well defined. It is primarily a financial arrangement with the governance and oversight of such placements remaining with the health board. NSD has no role in the placement of patients within Scotland that are out of area of their local mental health provision. In addition, NSD has no role in the placement of patients within the private sector either in Scotland or in England.

Funding applications for these NSD cases specifically for mental health can only broadly be made for:

- patients to be accommodated in NHS England commissioned providers of high secure care for women;
- secure care for adolescents:
- · specialist care for adolescents with learning difficulties; and
- mental health inpatient treatment for deaf people.

Funding requests are for access to a pool of funds that NSD have delegated responsibilities to administer, on behalf of all health boards in Scotland. The health boards contribute to the pool on a proportionate basis that equates roughly to each area's respective population; NHS health board chief executives have agreed this approach. Under no circumstances can funding be used to fund care in the private sector. In this circumstance, health boards can, at their discretion, place and fund private sector care themselves.

There is a defined process for making an application to NSD, for funding out of area care. Local clinicians submit the request for consideration to their local out of area (OoA) panel, who then in turn submit to NSD. Both the commissioned provider and the responsible commissioner from the local health board are expected to review funding on an ongoing basis regularly.

The funding of all NHS England highly specialised/specialised care is overseen and administered by NSD with regular meetings with all health boards in Scotland.

NHS health board out of area panels

CEL 06 (2013)⁸ set out the procedures for establishing the responsible commissioner for an individual's care in the NHS. The guidance states that health boards have a responsibility to commission and provide health care services for people living within their boundaries, i.e. individuals who are "ordinarily resident" in their area. Where the health board has no local service, and the safety and wellbeing of the individual is of paramount concern, the underlying principle of CEL 06 is:

"There should be no gap in responsibility for the provision of health care, and no treatment should be refused or delayed due to uncertainty or ambiguity over which NHS body is responsible for funding an individual's health care provision."

Where there is no local service, the request to transfer an individual's care to a service out with the local NHS health board facilities falls into several categories. As noted earlier, these categories could include highly specialised services funded through NSD or jointly funded packages of care, where there has been an agreement made between an NHS health board and the local authority to fund the care that an individual requires.

The other out of area NHS funding options identified are:

- Extra contractual referrals (ECR);
- Out of area treatments (OATS); and
- Unplanned activity (UNPACS).

Extra contractual referrals (ECR) relate to treatments/services not normally provided locally by some NHS health boards' facilities or are provided through a service level agreement (SLA) with other NHS providers. In the NHS, ECRs are elective and typically represent low volume services and treatments; they do not include specialised procedures (this would be NSD funding). They are often provided by non-NHS health service providers, e.g. nursing care homes. ECR funding is taken from the NHS health board's revenue allocations.

Out of area treatments (OATS) applies to NHS cross-border activity between Scotland and the other UK countries i.e. England, Wales and Northern Ireland. OATS covers emergency treatment only and therefore by its nature is unplanned. There is no right of refusal by NHS boards as this is for emergency treatment.

Unplanned activity (UNPACS) is similar to OATS but relates to emergency NHS treatments provided to the local NHS board's residents elsewhere in Scotland. Like OATS, there is no right of refusal and funding is taken from the NHS board's revenue allocations.

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⁸ https://www.sehd.scot.nhs.uk/mels/CEL2013_06.pdf

Whatever funding option is being considered by the NHS board, the framework and process associated with an out of area placement is broadly similar across NHS boards in Scotland. An example of the ECR request for one of the health boards in Scotland can be found in Appendix 1.

Summary findings

When gathering the data based on the 2022 census report, in some cases, the representatives of health boards that we spoke with did not identify individuals who were receiving care and treatment out with their own NHS Scotland health board. Others were initially unclear about which individuals we were asking for information about, and looked to provide us with data on those who were being cared for in a social care setting. The data gathered for the Scottish Government census is provided by NHS staff, and if there are different internal processes for gathering this data, and the data is not verified for accuracy, then the overall information may not accurately represent the number of individuals who are out with the NHS services in Scotland.

Our key message is that if there are anomalies and inaccuracies in the data that NHS health boards gather, then commissioning and planning future services for people who have complex needs associated with their mental health or learning disability may be challenging.

We recommend that:

- 1. Scottish Government formally review the categories identified for publishing data on those patients who are out with their local health board area.
- 2. Scottish Government develop a data gathering process for out of area NHS board placements which is verified and accuracy can be assured.

For those who were out of their home board areas across NHS Scotland, there were some key findings from our visits. These highlighted a range of concerning issues, which had a direct impact on this group of individuals. The 2022 census data noted that individuals, on average, were treated and cared for, for three years and eight months out with NHS Scotland; of the 59 individuals cases we reviewed, 36 (61%) had been away from their original board area for four years or more, the longest being 28 years; we found the average to be more than eight years. We also heard that for most people, the reason for transferring their care was due to challenging behaviour, and that, of the group we met with, most people had a mental illness, or a learning disability. There was a greater number of people with dementia in census data that had been submitted six months earlier to Scottish Government compared to the data we received.

In NHS England, there are specific standards set out by the National Institute for Health and Care Excellence (NICE) where a transition is planned with an individual's inpatient mental health care team⁹; the Care Quality Commission (CQC) use NICE guidelines as evidence to inform their inspection process of NHS services in England. At present, there is no equivalent guidance set out for NHS Scotland. The NICE guidance has been developed to ensure that those with lived experience, and their families and carers, have a better experience of transition by improving the way it is planned for and carried out.

We found that, for a number of people we had contact with as part of this work, there were opposing views about concerns with a person's transfer between the new service provider, and those that would be funding the care (the originating health board). We heard the same from some of the relatives, who were concerned about their family member being moved out of their local health board area. We also found that not all of the people that we spoke with

⁹ Transition between inpatient mental health settings and community or care home settings (nice.org.uk)

were clear about the reasons for their transfer, very few had been given any detailed information relating to their move and for most, we could not find out who had been provided with support, and indeed what support had been made available.

Our key message is that individuals with lived experience should be as involved as possible in any transfer of care, their will and preferences should be clearly recorded and their support network identified and involved. Comprehensive information, in the most suitable format, should be provided and reviewed over the first few months of an admission. Links should be maintained with their home area (if applicable) and regular reviews established between the professionals in the service providing the care and those commissioning and funding it.

We recommend that:

3. Scottish Government should commission the development of a set of standards from referral to transfer with involvement of those receiving the care and treatment, their carers/family and those most important to them (as appropriate) that outline the key steps required for an inclusive, supported approach to planning an out of area placement.

When we asked people about their care prior to transfer, we heard it described mainly as "okay". More concerning to hear were the views of nearly 40% of those that could tell us that their care was either not too good or not good at all. 40 people (67% of the group) had transferred from an NHS facility, where they had contact with the same number of professionals in their previous NHS service as they did after they transferred to the current service that we met with them in. The main difference here was that after transfer they saw members of the multi professional team, such as psychiatry and psychology, more frequently.

People told us that had there been more access to support and a different type of environment there may not have been the need for transfer. Having moved out with their home board area, it was reassuring to hear that for most of those that could tell us, they had felt that the move had been positive. More staff who were available to help and offer support, more involvement and choice with their care, their daily routine and their activities were all highlighted.

It was also good to hear that most of the carers/relatives felt that they were involved in decisions about their relative's care, and able to attend reviews; there was also some level of contact for all carers with the previous care team. From the carer's viewpoint, what was missing were plans for their relative's discharge, and their involvement with this.

Our key message that we heard about care and treatment was that a move from their local NHS Scotland health board had, for many, been a positive step, with people having more opportunities to regain and build on their skills. We found that there was more input into the individual's care from professionals such as psychologists and occupational therapists, with a greater emphasis on activity, both in the environment and out in the local community. However, what we heard less of was around the planning of what needed to be put in place to ensure that individuals could continue their recovery journey when transferred out of the independent health care setting they were currently in.

We recommend that:

4. NHS Boards who are funding an out of area placement should jointly develop and incorporate a structured plan with the independent healthcare provider that includes rehabilitation and engagement back to the local area where the person will be returning to.

We found that for most of the people that we were able to speak with about their plans for the future, whether that was returning to their home board area or somewhere else, they either did not know about this, or there were no plans in place. There was little detail about planned activities in relation to repatriation, but what we did find was that individuals and their relatives were not given regular updates, and were not fully informed about what some of the difficulties were likely to be for them to be discharged. We also heard about the impact that being out of area had on individuals and their relatives, mainly due to the distance required when travelling to visit, and the toll that this took on their relationships.

For both the current service provider and the funding service, there were concerns around effective discharge planning with different reasons why there was a lack of this taking place. We found that where discharge planning processes were happening, there was nominal representation from the funding health board, and at review meetings, the focus on goals to achieve a discharge were not well defined.

Planning being undertaken by the funding health boards at a strategic level was not then shared with either the individual, their relative or the current service provider.

Our key message is that for successful repatriation to an individual's local NHS Scotland facility, discharge planning should begin at the earliest possible opportunity, should fully involve the individual, their relative/carer and provide specifics on the support, resources and activities that the individual will need to achieve a safe and continuous recovery.

We recommend that:

5. NHS Boards develop and apply a set of discharge planning standards informed by cross agency multi-professional groups and those with experience (carers and people with experience of services) which focus on recovery and return to local areas.

Without an effective process around discharge planning between funders and the independent care providers, there is likely to be a missed opportunity for the local funding services to timeously develop and resource a service that meets the individual's needs and outcomes back in an NHS Scotland health board area.

With nearly three quarters of the funding for placements we considered coming from health budgets, we found that even where there was evidence of integrated approaches in the monitoring and support provided to an individual who was out of area, there was a lack of shared knowledge about discharge plans and the funding in place. At times, it was difficult to identify who was the responsible commissioner for a funded placement out of area, and gathering data on this was problematic.

We found that getting an overview of the cost per placement was a challenge. Different departments and people held the information about costs, and this varied across health boards. Costs varied as well, with some health boards being charged less than others for a similar service, and for others, there were additional costs for enhanced activities. Most funding services anticipated that these costs would increase in this financial year.

We were able to see that for two boards in the north of Scotland, there was an annual approximate cost of £4,000,000 for out of area placements, and this is likely to be a conservative estimate. Where there are opportunities to develop a more regional service, for example one in the North region of Scotland that could serve Highland, Grampian and the Islands, this would cut down the impact of travel for people in these areas and in the longer term be more cost effective, but definitely more beneficial for individuals and their relatives/carers.

Our key message is that even with a conservative estimate for costs, the NHS health boards in Scotland are paying over £13 million per year for individuals who are in an out of area placement.

We recommend that:

- 6. Scottish Government review the monitoring of the funding costs for out of area placements and sit this with a national organisation such as NHS National Service Scotland, through the National Services Division, for centralised oversight and scrutiny.
- 7. Scottish Government consider a human rights and health economics based approach as to whether regional units should be developed for those individuals who are considered at greatest risk of being out of area.

Chapter 1: The individuals who are out of area

What we did

The published data from part 2 of the Scottish Government's in-patient census does not provide details of the type of service in which individuals are receiving care. It was not possible to know whether a person was in a high or medium secure forensic service; or whether they were in a private/independent service in their local area but not an NHS Scotland facility; or whether they were in an NHS Scotland facility that was a national or specialist unit, such as the Robert Ferguson unit in Edinburgh.

In order to gather more detailed information than that provided by the department of Health and Social Care Analysis, we contacted the Chief Executives of all NHS boards in Scotland in November 2022. We provided them with an outline of what would be involved with our themed visit, and asked them to inform the relevant leads in their mental health and learning disability services. In order to gather up-to-date information of individuals who were receiving care and treatment out with the local board area, we contacted a range of health board staff – senior managers, clinical governance staff, commissioning officers - and asked them to provide a copy of the part 2 data, including any amendments since their submission in April 2022.

The data published in the Scottish Government 2022 census noted the following:

Table 2

| NHS Board responsible for funding | 2014 | 2016 | 2017 | 2018 | 2019 | 2022 |
|-----------------------------------|------|------|------|------|------|------|
| NHS Ayrshire & Arran | 34 | 29 | * | * | * | 20 |
| NHS Borders | * | * | * | 27 | * | 16 |
| NHS Dumfries & Galloway | 10 | * | * | * | * | * |
| NHS Fife | * | * | * | * | * | 7 |
| NHS Forth Valley | * | * | * | * | 0 | 0 |
| NHS Grampian | 18 | 14 | 14 | 15 | 16 | 20 |
| NHS Greater Glasgow & Clyde | 11 | * | * | * | * | * |
| NHS Highland | * | 10 | * | 20 | 19 | 9 |
| NHS Lanarkshire | * | 10 | 14 | 15 | 15 | 43 |
| NHS Lothian | 20 | 25 | 24 | 59 | 24 | 22 |
| NHS Orkney | * | * | * | * | * | * |
| NHS Shetland | * | * | * | * | 0 | 0 |
| NHS Tayside | 16 | 13 | 11 | 14 | 12 | * |
| NHS Western Isles | * | 12 | * | 13 | * | 8 |
| Totals | 143 | 137 | 109 | 197 | 126 | 162 |

^{*} suppressed to maintain confidentiality

Methodology

At the outset, we opted to include only those over the age of 18 years. We also did not collect data, or review the care and treatment, of individuals who were in high and medium secure services (n=18); there is a defined care pathway for mentally disordered offenders (MDOs)

and resources for this group are directed to these specific NHS forensic services or via funding agreed NSD.

Where possible, we wanted to meet with those who could provide us with details about the care and treatment provided. Where an individual had been out of their NHS board area for a period of more than two years, we specifically wanted to visit them even though it may not have been possible to gather their views about the impact of their care away from their home board area. This enabled us to at least review the individual's care and treatment.

Data was gathered from all health boards although it took time to identify the best source to provide what was needed. There was variation in the type of reporting template. Not all boards that responded used the SG census excel sheet that we had requested them to use; this would have provided better consistency and comparison of data with the census findings and ours, which were approximately six months later. For a number of boards, we found anomalies and inaccuracies.

We had expected a sample of approximately 162. After screening out individuals in high and medium secure services, and those who were being treated in a non-NHS setting that was in their local health board area (so were not out of area), as well as individuals who were in specialist NHS services in Scotland, but not in their local area i.e. the national brain injury unit, we had a sample size of 86 to review.

From the 86 individuals, we wanted as varied a group as possible. We wanted to meet with men and women, across a broad age range, and who had either or both a mental health diagnosis, or learning disability. We also wanted to review the care of as many individuals as possible from all of the health boards who had identified as funding people in an out of area placement. At the time of our request, a few boards had none.

From the data, we could see that there were several independent (private sector) care provider services, both in Scotland and England, who had a number of people from different NHS health boards in Scotland. We contacted them to confirm that the people we were reviewing were in their service. At this time, we also asked those independent care providers if they had any other individuals in their service from NHS health boards in Scotland, and some confirmed they had. We found that the data provided by some health boards had not identified those individuals who were out of area.

Of the possible 86 people, we were able to review the care and treatment of 59 people. For pragmatic reasons, there were a number of individuals who were supported in services in England where the individual themselves was not able to provide the detail we needed about their care and treatment, and given the geographical distance, this group of people were not included. For others, when we were making contact with the service provider and requesting permission from the individual to meet with us, some people declined; as we wanted, wherever possible to speak directly to the person receiving care and treatment, this group was also not included.

We had developed a series of four questionnaires, in part, based around the census data, and we had incorporated some of the findings and recommendations from the *Coming Home* report into our questions. Where possible, we met with the individuals in the care setting, however, for some, the extent of their diagnostic symptoms limited participation. However, we reviewed the individual's care records, and spoke with the staff team providing care. If there was a relative/carer involved, we invited them to provide us with their views, and similarly,

where there was a commissioner from the NHS board funding the out of area placement, we spoke with them.

In total we had a further 121 interviews and contacts with relatives/carers, clinical staff and professionals.

Table 3

| Group | Collection method | Distribution |
|--|------------------------------------|--|
| Relatives/carer | Telephone/postal | A questionnaire was either discussed or distributed via the care provider at the time of the visit. Follow up contact was made where an interview had been agreed. There were 12 relatives/carers who agreed to a telephone interview. |
| Individuals | Face-to- face/records review | A questionnaire was completed by a Commission practitioner with the person (total 46). 59 records were reviewed. |
| Staff from out of area care service | Face-to-face | A questionnaire was either discussed or distributed to the care provider prior to/at the time of the visit. There were 58 questionnaires completed. |
| Staff from originating NHS health board (funder of service) | Telephone/email | A questionnaire was either sent or discussed by a Commission practitioner with the identified professional involved in the out of area placement. A total of 51 questionnaires were completed with staff. |

Focus of our questionnaires

We wanted to gather details on the individual's transfer from their home health board area to their current placement. Contact was with the four main groups set out in Table 3, and there were some overarching areas we wanted to cover:

- 1. The referral process and the involvement/engagement with the individual and their carer.
- 2. Care and treatment available prior to being moved out of area and the impact of this.
- 3. Details of the current care and treatment from all four groups involved in the process
- 4. Funding and repatriation plans with own health board area.

Analysis

Data analysis was carried out using Excel, R and NVivo. Some of the questions were incorporated into two or three of the questionnaires; this enabled us to gather a holistic view of the individual's pathway. Where the responses could potentially compromise the anonymity of an individual i.e. where there was only one person for that area, we have suppressed the data for this.

Where possible, the direct comments and contributions gathered during the Commission practitioners' contact with people were aligned to the four overarching areas noted above.

What we expected to find

The census data found that the majority of individuals were treated in private facilities in Scotland, because the "facility to meet the patient's needs does not exist within NHS Scotland and there is no alternative to admission". Most of the patients who were out of NHS Scotland care were male, and were older than their counterparts in NHS facilities.

The most common diagnosis for patients treated out with NHS Scotland was dementia followed by a learning disability; the category of mental illness and personality disorder were the others listed although the census indicated that individuals were likely to have multiple diagnoses.

The average number of days for patients treated out with NHS Scotland was approximately three years and eight months. The 2022 census reports that this is almost 10 times longer than that of patients treated within NHS Scotland facilities.

What we found

There were 32 men (54.2%) and 27 women (45.8%) in the group of those whose care we reviewed; this was broadly representative of the gender mix of the overall sample of 86 people that we received data on.

The age ranges for the group were:

Table 4

| Age Range | n (%) |
|-----------|-----------|
| 18-24 | * |
| 25-44 | 29 (49.2) |
| 45-64 | 20 (33.9) |
| 65-85+ | * |

^{*} n<5 suppressed and secondary suppression to maintain confidentiality

The health board areas where the 59 individuals originated from:

Table 5

| Health board | n |
|--|----|
| NHS Ayrshire & Arran | * |
| NHS Borders | 5 |
| NHS Dumfries & Galloway | * |
| NHS Fife | * |
| NHS Forth Valley | * |
| NHS Grampian | 9 |
| NHS Greater Glasgow & Clyde | 6 |
| NHS Highland | 12 |
| NHS Lanarkshire | 5 |
| NHS Lothian | 11 |
| NHS Tayside | * |
| NHS Island Boards (Western Isles, Orkney & Shetland) | * |

^{*} n<5 suppressed to maintain confidentiality

We wanted to find out what type of setting people were in prior to their transfer. 40 (67%) came from an NHS service, eight (13.5%) came from other types of settings such as prison, six (10%) were from independent private health care providers and the remaining individuals came from either a children and young people's service, or from their own home (n=5, 8.5%)

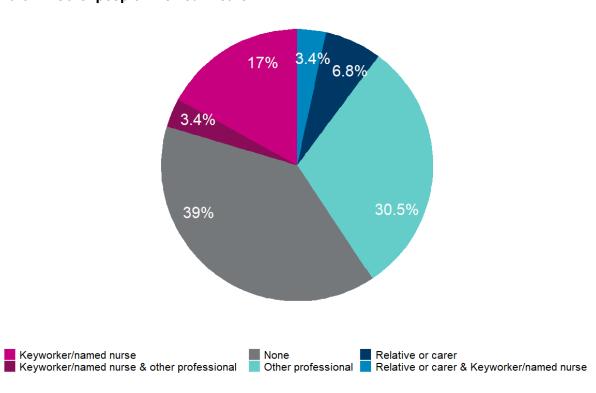
The geographical areas where the individual's current care was being provided in were:

Table 6

| Geographical Area | n (%) |
|--|------------|
| Ayrshire & Arran/Dumfries and Galloway | 22 (37.3%) |
| Greater Glasgow & Clyde | 12 (20.3%) |
| Tayside | 7 (11.9%) |
| England | 18 (30.5%) |

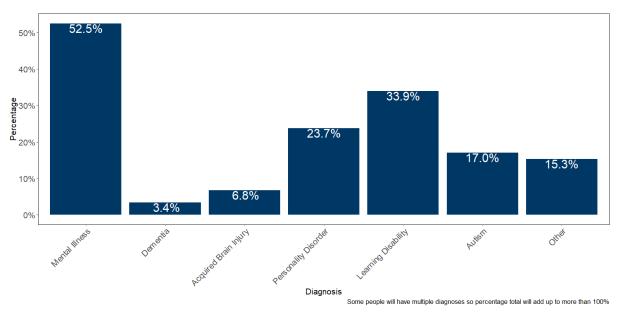
In addition to speaking to the individuals, we also spoke with people involved in their care and treatment where possible (chart 1 below).

Chart 1 - Other people involved in care



We also asked about diagnosis, with a significant number of people having more than one. Chart 2 below shows the number and percentage of people with the diagnoses.

Chart 2 – Diagnostic groups



'Other' categories included people with an eating disorder (specifically anorexia nervosa), Huntington's disease, linguistic disorder (deafness), mood disorder and dissociative convulsions, and tuberous sclerosis.

We also looked at the legislative frameworks that were in use for the group and found the following:

Table 7

| Legislation | n (%) |
|-------------------|-----------|
| ¹⁰ AWI | * |
| ¹¹ MHA | 48 (81.3) |
| MHA & AWI | * |
| Informal | * |

^{*} n<5 suppressed to maintain confidentiality

One of the key areas that we wanted to look at was the length of time individuals had been placed out of area. We found that 11 individuals had been in their current placement for less than two years; 6 (10%) were up to six months, with a further five who had been there between seven and 24 months (8.4%).

For the majority (n=48, 81.6%), their out of area stay spanned from two years plus, with the longest being 28 years.

¹¹ The Mental Health (Care and Treatment) (Scotland) Act 2003 (MHA)

¹⁰ The Adults with Incapacity (Scotland) Act 2000 (AWI)

Table 8

| Duration | n (%) |
|----------------|------------|
| 2 to 5 years | 24 (41.2%) |
| 6 to 10 years | 16 (27.1%) |
| 11 to 15 years | 6 (10%) |
| 15 years + | * |

^{*} n<5 suppressed to maintain confidentiality

Given the length of time that some individuals had been out of their own board area, we looked at the possibility that their discharge from their current service provider was delayed. We found that for the majority, it was either unclear (n=11, 18.6%), or the information was missing from the care records we reviewed (n=12, 20.3%), or there was no delay (n=30, 50.8%). There were six people whose discharge from the care setting was delayed, and we are in the process of following up on these cases.

Chapter 1 summary

The group of people who are placed out with their home health board area appear to have complex needs, with comorbid diagnosis. They have mostly had care and treatment in NHS Scotland, but have required to be placed elsewhere. For the majority, use of formal legislation has been used.

We reviewed the circumstances of individuals from nearly every health board in Scotland, and found that some areas such as NHS Highland and NHS Lothian had a higher number of people that were funded out of area. What was notable was the difference in data from the SG census, and our data that was gathered a little more than six months later, e.g. NHS Lanarkshire reported 43 people in the SG census, and in our data, it was 20. We also found that gathering this information was challenging, with different sources providing this, in various formats.

We recommend that:

- 1. Scottish Government review the categories identified for publishing data on those patients who are out with their local health board area.
- 2. Scottish Government develop a data gathering process for out of area NHS board placements which is verified and accuracy can be assured.

Chapter 2: Referrals and transfer of care

What we expected to find

At a time when a person's care is about to change, and a referral is being made to an out of area placement, we would expect to find that both the individual, and their relative/carer are actively involved in this, that they were given a choice, asked their views and that these formed part of the process.

We would expect that through the course of a transfer of care that the rationale for it was clear, that there were estimated timelines set for each stage of the process, that there are well-defined outcomes of what should be achieved, and that what would be provided was in the person's best interests. We expect that the least restrictive option would be considered, and that how care and treatment was to be reviewed would be identified at the time of referral, as well as consideration of discharge options.

What we found

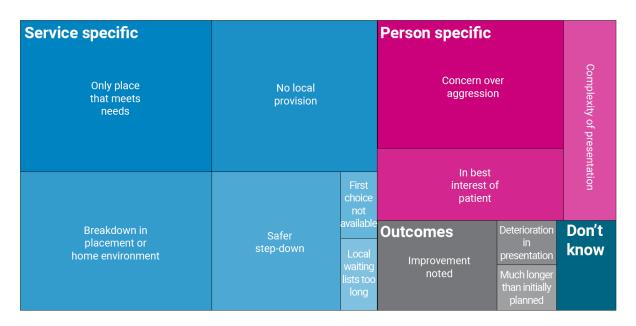
In NHS England, there are specific standards set out by the National Institute for Health and Care Excellence (NICE) where a transition is planned with an individual's inpatient mental health care team¹²; the Care Quality Commission (CQC) use NICE guidelines as evidence to inform their inspection process of NHS services in England. At present, there is no equivalent guidance set out for NHS Scotland. The NICE guidance has been developed to ensure that those with lived experience, and their families and carers, have a better experience of transition by improving the way it is planned for and carried out.

Views of the services

We asked the original funding service for details relating to reason for referral (Chart 3 below). Those most frequently given related to service provision i.e. no local services being available or not meeting the needs of the patient or being a safer step-down option. Other reasons were more person specific, such as concerns over aggression, complexity of presentation or the transfer being in the person's best interests.

¹² Transition between inpatient mental health settings and community or care home settings (nice.org.uk)

Chart 3 - Reason for referral



Some of the comments from the funding services gave more detail about the need for a referral. We heard:

"He was admitted from a specialist service that could no longer manage due to an increase in aggressive behaviour. Over the years he had had many admissions to a mental health hospital. His presentation was often linked with high levels of agitation and aggression."

"There is no specialist eating disorder inpatient services in the West of Scotland for NHS Lanarkshire. This should be raised as a national issue. Severe anorexia nervosa can be treated in some NHS adult wards but in this health board area, decisions are made on a case by case basis whether they can meet patients' needs locally."

"There have been long periods of admission to the hospital and he had spent many years in rehab and an intensive psychiatric care unit. However, due to increased assaults and risk, these services could no longer manage and he was transferred to the private clinic."

While the funding service mainly noted a breakdown in placement and a lack of local service provision as the reason for referral, we heard the reasons for admission from the current independent providers were:

Table 9

| Admission Reason | n (%)* |
|-----------------------------------|-----------|
| Challenging behaviour | 37 (63.8) |
| Learning/ Intellectual disability | 10 (17.2) |
| Autism | 5 (13.2) |
| Forensic/ secure needs | 19 (32.8) |
| Other | 21 (36.2) |

We asked the current independent service provider if there had been any concerns and/or changes as a result of the transfer to the service. We were able to gather the views for each person from both the current service, and match this with the funding service for 37 individuals (63%). For the remainder, either the current service provider or the funding service had not indicated a concern about the transfer (n=22). There was agreement about concerns for 18 individuals (49%) and for nine (24%) there were no concerns raised for either service with the transfer. However, for the remaining ten people (27%), there were opposing views about the concerns each service had with the current service having noting their concerns as a result of the transfer for five individuals.

Table 10

| Concern/Change | n (%)* |
|---|------------------------|
| Increased conditions of security | 16 (27.6) 21 (36.2) |
| More intensive input from health care professional | 21 (36.2) |
| Increase in harmful or disruptive behaviour from individual | 9 (15.5) |
| Loss of contact with family/friends community | 13 (22.4) |
| Other | 2 (3.4) |

^{*}there can be multiple concerns or changes so will add up to more than 58 & 100%

Of those who said there had been issues, we heard:

"Managed through positive behavioural support over period of seven years. The team now report much improvement in his behaviour and presentation."

"She would like to be living nearer to home. She requires a degree of restriction to maintain safety in this setting, though it is likely that this would broadly need to be replicated in any setting. She has made improvements but still presents with challenges."

"She has had a difficult transition to our service and her challenging behaviour has continued. She is a distance from her family but does have regular contact."

Views of those with lived experience

We asked the individuals if they were given a reason or an explanation when they were being moved to an alternative setting. For some of the 59 individuals, due to the impact of their illness, they were unable communicate directly with us (n=15). For the remainder of the group, 28 people told us that they had been told about their transfer (47.5%), three people (5.1%) said they had not been given a reason or explanation and 13 people (22.0%) did not know if they had been given information or not.

We asked who had given them an explanation about the move, and for those who were able to tell us, 32 people said that it was a medical professional, two told us that no one had explained the transfer to them and five people could not remember, were unsure or did not know.

We wanted to hear more details about who and how the explanation had been given. We heard:

"She described the move as 'positive', it was all about me. It felt like a smooth transition. It was a good move compared to restrictions in hospital. I get to do trauma work which has on occasion destabilised me but the move has settled me down."

One person told us he couldn't remember much about the move but did say "I wasn't really involved. I was made to come here."

We asked whether people were given information verbally or in written form. 17 people (28.8%) said they were given information verbally as to why they were being moved, three (5.1%) said they had received information but did not give details of whether this was verbal or written, two said they received information from a doctor (3.4%). Only two (3.4%) people said they had both written and verbal information. Three people (5.1%) were given no information, one (1.7%) could not recall and one (1.7%) did not know if they were given information or not.

We also wanted to know if anyone had offered support to the person, such as their doctor, or advocacy. Sixteen (27.1%) people said they had support, while 10 (17.0%) said they had no support. 33 people (55.9%) did not provide an answer.

We asked people to tell us what they thought or were told was the reason they were moved to an out of NHS area service. There was a range of views, with a mixture of some that were happy to move, and others who were unhappy. People also talked about not having a choice, or not being involved, but for others the move was explained to them.

We asked people how long the transfer process took for them. For more than half of those we met with, we could not get any additional information about the timescale between being told of the move, and the actual move itself (n=35, 60%). We had varying responses from the others, with some giving us the amount of time it took (n=6, 10%) to others telling us it was a quick process (n=11, 19%). However for some, they described the transfer as gradual and planned (n=7, 11%).

We heard that for some, transfer had been a positive experience:

"I got a leaflet supplied about the unit, as well as new psychiatrist, psychologist and nursing staff. I met everyone before coming."

"I wasn't bothered at the transfer; I wasn't well enough to make the decision. It was the best thing to happen to me. I feel like I've been wanted here."

But for others:

"I didn't want to come here, I don't find it helpful and would rather be back at my local hospital, or even better, at home."

"I was just given an injection and sent down to England."

"No choice, no say and no involvement."

We asked those relatives that had agreed to speak with us about the care for their family member. We had 12 completed questionnaires; five were parents and seven were other relatives.

All respondents told us they were made aware of the reason for transfer out of region, and most were positive even if they had concerns:

"I was mostly relieved because he was leaving the hospital he was in."

"The psychiatrist informed me that there was nothing else that could be done. As a result they offered a placement in England but I refused due to the distance and instead a place was offered here and this has been much better."

"We were encouraged to visit the service and ask any questions that concerned us."

"I was involved in the decision and had given it careful consideration, due to the distance from home, but was keen for him to access good rehabilitation."

We asked if family/carers were consulted/involved in the decision, 83.3% said that they did feel consulted/involved in the decision, while 16.7% felt that they were not.

"We were not consulted or invited to any meetings by the NHS or council. It was all undertaken via a meeting which we were not involved in. We instructed a lawyer for advice and wrote a letter to the social work department regarding their responsibilities... there was a take it or leave it attitude."

"Nobody discussed the plans for transfer..."

Only 8.3% said that they had objections to the transfer, while 91.7% had no objections. 33.3% of carers had concerns about the transfer while 66.7% had no concerns.

Some of the concerns were:

"Primarily it was the distance from home, and travel. And also concerns about a lack of local services to meet his forensic needs."

"We wanted him transferred to somewhere close to us. The choices given were limited and we didn't really have a choice. He had friends from the local area, he attended functions and groups locally and has lost all this."

"While we were concerned, we were more desperate for hope that her condition would improve. We always hoped that another hospital would do more."

We asked if carers were worried about any aspects of the transfer:

Table 11

| Worries | n (%)* |
|--|----------|
| Distance to travel | 8 (66.7) |
| Expense of travel | 6 (50.0) |
| Difficulty in maintaining relationship at distance | 5 (41.7) |
| Difficulty in contributing to care at a distance | 5 (41.7) |
| Difficulty in maintaining relationship with children | 1 (8.3) |
| Other | 2 (16.7) |

^{*}some carers will have cited multiple worries so answers will add up to more than 12 or 100%

When carers were asked if their relative had benefitted from this placement, 91.7% felt that they had benefitted with only 8.3% saying that they had not. However, even those carers who were positive about the transfer still had some concerns.

We heard the following positive comments

"He has only been there a few months, and he appears less distressed and appears to be enjoying all the activities on offer. He is seen by an OT and psychologist too."

"She is getting into a routine of breakfast/lunch/dinner and supper. I've noticed that her weight has increased and she looks a bit healthier."

"In some ways he has very much settled down. He will never be able to live by himself. The move has benefitted him."

Some of the more mixed comments we heard were:

"Compared to what he was like in the supported accommodation there has been a significant improvement. However, he remains off where he was two years ago. This is not due to the service he's in at the moment; instead he has not fully improved."

"Initially, yes when we saw some improvement, but the changes in doctor and staff shortages have impacted on his care, and I feel that he should have been repatriated in the 2021."

"I'm concerned about lack of structured activity and community engagement."

Chapter 2 summary

Both the current service provider and the funding service (Scottish health board) identified that challenging behaviour was the reason why more than half of the people whose care we reviewed were referred out of the local health board area. Those funding the service acknowledged that for this group, it was mainly a lack of a local service to meet their needs that had driven the transfer. In response to this, the current non-NHS Scotland services have developed and now mainly provide the forensic and secure care needs required for this group of people.

Those that we spoke with – the individuals and their relatives – were mixed in their opinions about their involvement in the referral and transfer process. Some were informed, and provided with information about the new service; for others it happened with little or no notice.

Again, we heard mixed reviews about the benefits of the out of area move, with some acknowledging that their health and wellbeing had improved (as did some relatives), but for others, being away from their own community and their family was a concern.

We recommend that the:

3. Scottish Government should commission the development of a set of standards from referral to transfer with involvement of those receiving the care and treatment, their carers/family and those most important to them (as appropriate) that outline the key steps required for an inclusive, supported approach to planning an out of area placement.

Chapter 3: Care and treatment - the before and after

What we expected to find

The needs of the individuals who are referred to services out with their home health board area are described as complex and challenging, and the care and treatment from these independent and/or specialist healthcare providers should be tailored and personalised to support the individual's recovery.

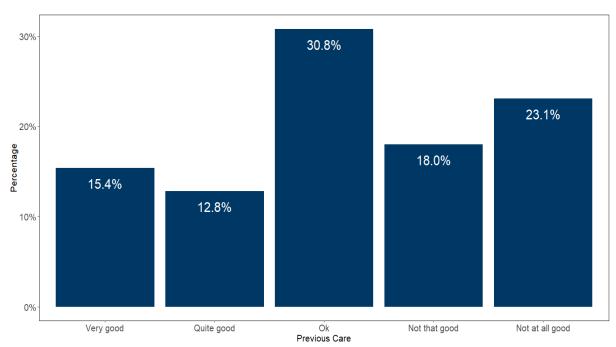
What we would have expected to find were comprehensive packages of care, with an outline of the timescale for each stage in the process, clear treatment goals that could evidence the individual's progress, and robust risk management plans that evidenced how risks could be managed positively and therapeutically. We would have expected to see strong engagement with both the individual, any relative/carer that was involved, and effective communication with the funding service.

What we found

Previous care and treatment

We wanted to find out from our sample of 59 people what they thought about their care before they moved to the out of area placement. 11 people thought their previous care was very good or quite good, a further 12 felt their care was okay, and 16 people felt their previous care was not that good or not at all good. 20 (34%) people did not, or were unable to, give us their views.

Chart 4 - Thoughts on previous care: views prior to transfer provided by individuals with lived experience



We asked who had been involved in the individual's care prior to their move out of their health board area. For some, there were multiple professionals involved in their care and treatment.

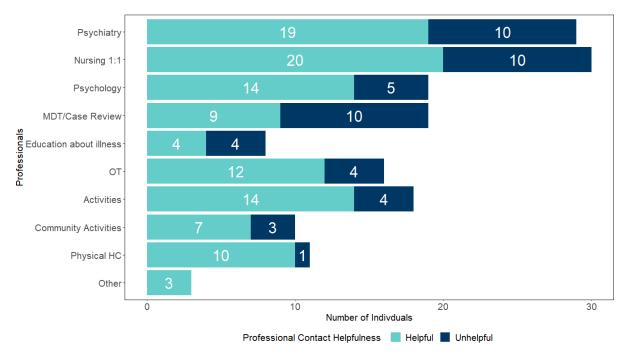
Table 12

| Involved in Care | n (%)* |
|--|-----------|
| Doctor | 40 (67.8) |
| Nurses | 39 (66.1) |
| Activity Co-ordinator | 12 (20.3) |
| ОТ | 16 (27.1) |
| Psychologist | 14 (23.7) |
| Family | 18 (30.5) |
| Someone else e.g. advocacy, dietician, social worker, chaplain, MHO, Pharmacist, speech & language | 19 (32.2) |

^{*}there will be multiple inputs so does not add to 59 or 100%

We asked individuals for their views about what was available for them in their previous setting, prior to transfer:

Chart 5 - Individuals' views on contact with professionals, pre-transfer



We heard:

From one person who said that life in the IPCU was "boring" and he has little memory of having things to do, or getting out of the ward. Being in his home area made it easier for his grandfather to visit him. He reflected on being happy overall in "getting out of the IPCU. I was overmedicated, on clozapine, and I became very unwell and was rushed to hospital."

Another person told us that her responsible medical officer (RMO) at her old hospital would help and she met with her social worker and mental health officer every 2 weeks. However, she would "leave the hospital and go out and drink."

We wanted to find out if people thought that had their care and treatment been managed differently, whether that would have changed the need for transfer. 12 (20.3%) people thought they could have had access to more support, 11 (18.6%) thought staff should have been better trained or been more knowledgeable, 11 (18.6%) thought there should have been a different type of environment, and four people (6.8%) felt there should have been more family/advocacy/legal involvement.

12 people (20.3%) thought something else would have helped e.g. being on a different ward or visits home.

We heard that 16 people (27.1%) were still in contact with someone involved in their previous care, but 25 (42.4%) said they had no contact; 18 (30.5%) did not answer this question.

Current care and treatment

We wanted to hear about the impact of the move on the individuals and their relatives. We also looked at what the current service was providing, specifically to see if there were any differences from the home health board.

In relation to the impact of the move, 22 people told us that the move was good or quite good, nine said it was okay, but seven felt the move was not that good or not at all good. 21 people did not answer or were unable to answer.

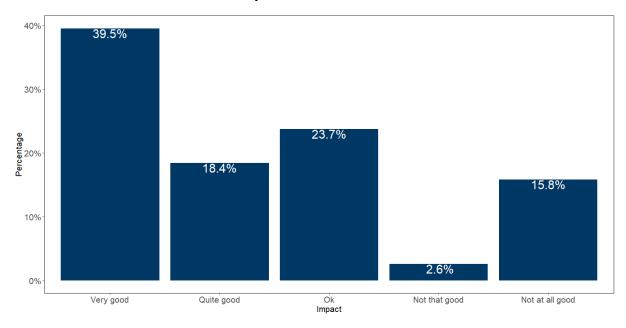
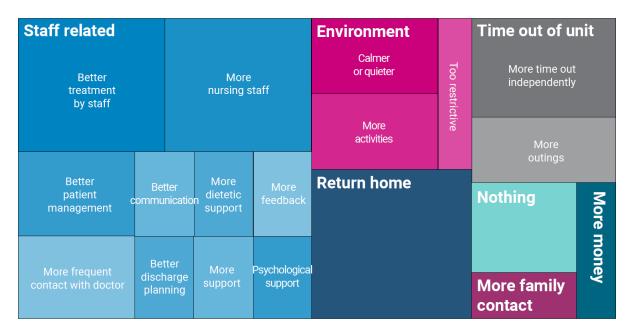


Chart 6 - Individuals' views on the impact of the move

When asked about whether there were any aspects of the current care that people thought could be better, most references related to staff e.g. more support, more nursing staff, more frequent meetings with doctors, better communication, better treatment by staff and better discharge management. Time away from the unit was highlighted, in the form of outings or more independence. There were comments about having a calmer or less restrictive environment with more activities. More family contact was mentioned, as was returning home, and having more money.

We heard from some that nothing could make it better.

Chart 7 - Individuals' views on aspects of current care that could be improved



In separating out the different aspects of staffing, environment, choices in daily routine, choices with activities, involvement and planning in current care, restrictions and support from others, there were difficulties getting a clear sense from the group of individuals whose care we reviewed about what was better with their care since transfer.

However, at least half of the people (n=29) were able to give us their view on the aspects below.

Table 13

| Different aspects of current care | Strongly agree/ Agree | Neutral | Disagree/ Strongly disagree |
|--|-----------------------------|---------|-----------------------------------|
| More staff available to help | 63.3% | 16.7% | 20% |
| Current environment better than previous one | 48.3% | 20.7% | 31% |
| More choice with daily routine | 53.8% | 30.8% | 15.3% |
| Choice of activities in current setting | 65.2% | 21.7% | 13% |
| More input into my current care | 57.5% | 34.8% | 8.6% |
| Change in restrictions | 47.8% | 30.4% | 21.7% |
| There is planning around my care | 59.1% | 36.4% | 4.5% |
| Good support from others | 61.8% | 34.8% | 4.3% |

Most people we spoke to felt that their care was better now than before, 13.6% strongly agreed, 54.5% agreed. 13.6% disagreed and did not think their care was better, and 9.1% strongly disagreed

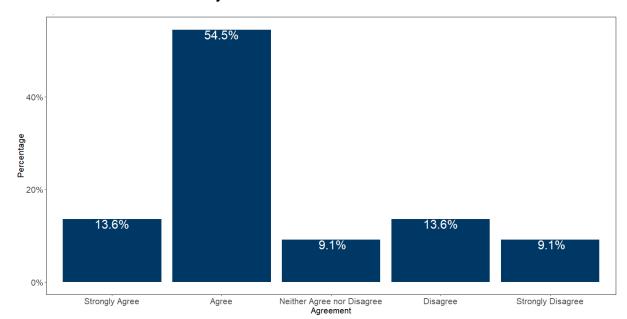


Chart 8 - Individuals' views: my care is better now than before

Direct comments from those that spoke with us were mixed when telling us about their current location. Some were positive:

"Bowling, Cinema, KFC, McDonalds, pub once a week for a pint. 1:1 once per week - helps speaking to a nurse."

"Support from dad. More access to phone/tablet. Staff are amazing. The OT's have helped me with baking, cooking, walk, shops. Is making me well. Mental health staff, doctor, charge nurse are all amazing. More 1:1 with staff. Best ward in 23 years."

"I wish I had come here years ago as I would have not lost all these years... Better age appropriate support required. Staff are so committed."

To more mixed views:

"My care is better than before - better but slightly more monitoring. Better environment as less drugs and less chaotic. Able to go to shops, movies, gym, take bus with staff. Go for meals, shopping with sister. Access to mobile phone".

"Social environment. More access to community. Not so much access to nurse and health care assistant. Don't feel listened to - nurses do not do any counselling/helping of therapeutic/coping skills."

To the negative opinions:

"I am restrained three times per week to receive forced feeding. It used to be three times per day. It is awful. I would prefer to be at home. The MDTs are not really helpful. I don't see any difference from being here."

"This ward is not as good as where I was before. There is no choice of activities - take it or leave it. Only a ward phone - not allowed mobile. I attend the ward round monthly."

"Would like to have more access to family, different activities, would like to cook. Just give me a bag of lentils, a ham hock and some tomatoes to cook with"."

We asked people for their views on what has been helpful, or unhelpful with the move.

Figure 1

```
environment less mum feels input staff want contact support mental also time get improved feel stay able better family move miss now away can see good like happier cope 4th home positive didn't confidence feel sister 'chilled health regularly
```

We had 15 different people tell us about better care and treatment, and about the contact with their family. However we did hear a number (n=7) of comments where the individuals told us there was less family contact.

We had a mix of positives:

"Better relationship with dad. Improved opportunities to spend time with family. I would stay here for a lifetime if I could."

""It's been really positive being here. It wasn't good where I was before, but here, I get to see my family".

And some mixed responses:

"Improved my quality of life, and it's improved my confidence, I can now get out and feel I have the strategies to cope. Hardest aspect is being so far away from my family."

"Great move, only issue is seeing family more regularly. They are my rock. I want to see them more regularly. I have been up to [home location] and this is the first time in many years."

"My mental health has improved overall and I have more freedoms here. I am happier as my medication has changed and I also see a psychologist. My mood feels much more stable and I am more confident. I do miss my family, my mother and my sister in particular but I can speak to them on the phone and I have been able to go home with a nurse escort on occasion."

And some negative responses:

"It's been a backward step for me. I can't see my mum I am so far away from home."

"I miss Scotland and my mum. I want to be back to Scotland. Get out more and have more freedom. I yearn to get back."

"Less contact with my father. I'm less confident; everything you try to do is wrong."

Our final question to people about their current care and treatment was to ask their views on involvement. We asked people about how supported and safe they felt in their current care setting, and whether the setting was meeting their needs and involving them in decisions about their care. We heard:

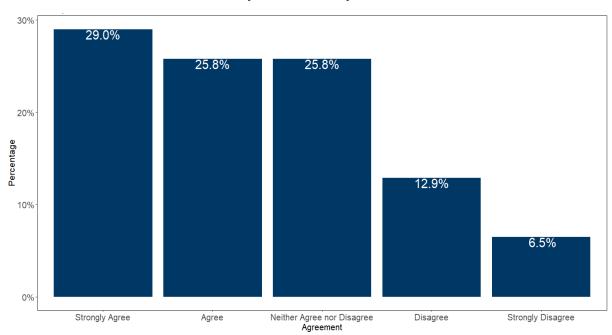


Chart 9 - Individuals' views: I am fully involved in my care

Views from the relatives about the current care and treatment

We wanted to hear what the relatives' general feelings were about the placement, and if there was anything they wished to tell us about the care and treatment that their family member was receiving on the ward.

We have chosen some feedback that is similar to that of our group of individuals, in that there are some positives:

One relative told us "He feels that now in his current ward, his brother is treated with respect and dignity and that he is the calmest and happiest he has seen him in many years. He feels that their knowledge of the illness has helped manage him well, commenting that there were no specialist services in Scotland."

"I consider that this current placement has saved my son's life. I think the MDT approach and the increased staffing levels have made a difference. His OT has been extremely helpful. The service phone and update us regularly, and we attend both MDT and CPA meetings and have good communication with the doctor."

"Can't fault the care. All the staff helpful and friendly."

"I did not think that the last service looked after my relative well. There was poor communication, disinterested staff and a shabby and unclean environment. I'm happy that he's been transferred to here it's like night and day."

And a mixed view:

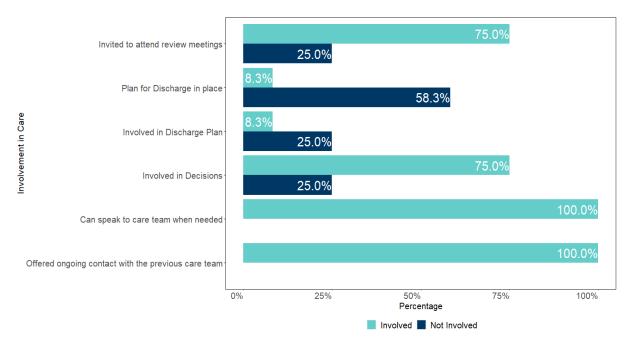
"I feel she is well looked after, in her current ward, but she has been there such a long time I feel she has become institutionalised. I feel she is now less confident than when she was first admitted. She has been here since 2013."

And some negative opinions:

"I don't think the care has been very good. I've felt that the focus was on the eating and not her mental health. By only treating the symptoms, and not the cause, she'll just relapse".

We asked the relatives for their views on being involved:

Chart 10 - Carers' involvement in care



We had some further feedback about the care team:

"Sometimes dependent on how busy they are I may have to wait until the next day before they call back. It is always easier if his key worker is on, they respond and know [person's name] very well."

"They are very accessible, and during Covid they arranged Zoom virtual visits, which he enjoyed as it gave him the chance to meet with his wider family on line."

Another relative told us that she "sometimes gets a call from the RMO out of the blue and every now and then. She "usually has to phone and chase them up; she keeps a diary and records when she hears from the care team."

And about reviews, our Commission staff fed back what they were told:

"Attends three monthly meetings usually in person, she does not attend the weekly reviews (she is invited but is not keen on virtual contact for the meeting)."

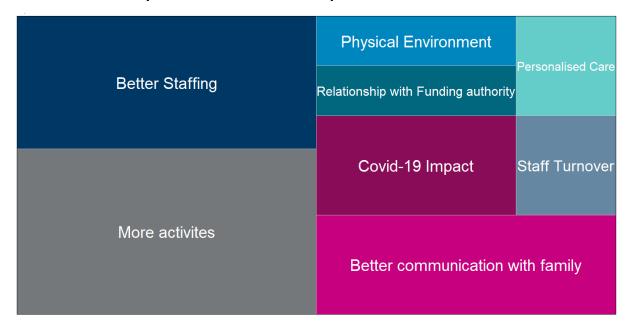
"She regularly attended the MDT and review meetings."

"Not fully, and the carer is not always in agreement with the plans."

"Yes, but the carer says that she has a heck of a job getting the minutes and has to push to get them."

We also asked carers if there was anything that could be improved, and there were a number of themes that emerged.

Chart 10 - Carers' opinions on what could be improved

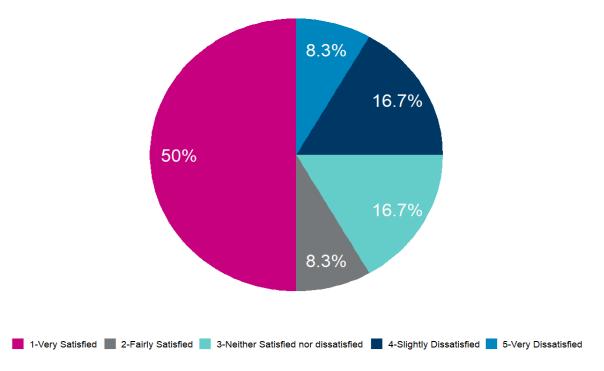


One carer told us that she "felt that her son was a fit healthy young man who would benefit from more meaningful activities in his life", she described him as "having lots of energy". She stated that he is only out twice a week and that this was insufficient to his needs. She feels there is "a high staff turnover and is unsure if there are staffing vacancies."

We heard from that there were issues with staffing in the ward, access to all therapies, that there could be better community links, and in communication with the family. Also the carer felt that the funding authority have never been supportive, and "as they are funding the placement, they should have an interest in what is being provided to the patient".

We asked how satisfied the carer was with the care and treatment being provided:

Chart 11 - Carers' overall satisfaction



Current service providers activities

We looked at the care files to assess whether they held key documents/records and information relating to the following:

Table 14

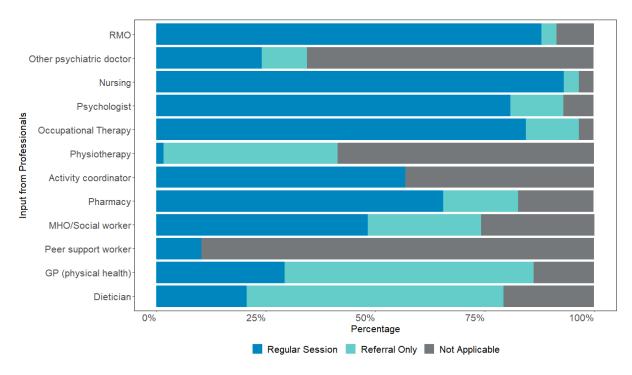
| The care record contained: | n (%)* |
|---|-----------|
| Evidence of patient involvement | 53 (91.4) |
| Advance statement | 19 (32.8) |
| Contact with the family | 41 (70.7) |
| Care plans | 55 (94.8) |
| Minutes of case reviews or care programme approach mins. | 50 (86.2) |
| Treatment and therapies | 45 (77.6) |
| Specific assessments in relation to reasons for admission | 44 (75.9) |

^{*}the files contained a combination of all these so will add up to more than 58 & 100%

Input from professionals Table 15

| Access | Frequency | n (%) |
|--------------------------------------|--------------------|-----------|
| RMO | Daily | 7 (12.1) |
| | 2-3 times per week | 11 (19.0) |
| | Weekly input | 33 (56.9) |
| | Referral only | 2 (3.4) |
| | N/A | 5 (8.6) |
| Other psychiatric doctor | Daily | 2 (3.4) |
| . , | 2-3 times per week | 8 (13.8) |
| | Weekly input | 4 (6.9) |
| | Referral only | 6 (10.3) |
| | N/A | 38 (65.5) |
| Nursing | Daily | 54 (93.1) |
| 3 | Referral only | 2 (3.4) |
| | N/A | 2 (3.4) |
| MHO/Social worker | Regular session | 28 (48.3) |
| e, coola. Ironio. | Referral only | 15 (25.9) |
| | N/A | 15 (25.9) |
| Psychologist | Daily | 1 (1.7) |
| 1 Gyoriologiat | 2-3 times per week | 9 (15.5) |
| | Weekly input | 31 (53.4) |
| | Other pattern | 6 (10.3) |
| | Referral only | 7 (12.1) |
| | N/A | 4 (6.9) |
| Occupational Therapy | Daily | 14 (24.1) |
| Оссирацопат гнегару | | 21(36.2) |
| | 2-3 times per week | · · · |
| | Weekly input | 9 (15.5) |
| | Other pattern | 5 (8.6) |
| | Referral only | 7 (12.1) |
| Dharaisthanan | N/A | 2 (3.4) |
| Physiotherapy | 2-3 times per week | 1 (1.7) |
| | Referral only | 23 (39.7) |
| A state of the state of the state of | N/A | 34 (58.6) |
| Activity coordinator | Daily | 21 (36.2) |
| | 2-3 times per week | 8 (13.8) |
| | Weekly input | 3 (5.2) |
| | Other pattern | 1 (1.7) |
| | N/A | 25 (43.1) |
| Peer support worker | Regular session | 6 (10.3) |
| | N/A | 52 (89.7) |
| GP (physical health) | Regular session | 17 (29.3) |
| | Referral only | 33 (56.9) |
| | N/A | 8 (13.8) |
| Dietician | Regular session | 12 (20.7) |
| | Referral only | 34 (58.6) |
| | N/A | 12 (20.7) |
| Pharmacy | Daily | 1 (1.7) |
| | 2-3 times per week | 3 (5.2) |
| | Weekly input | 16 (27.6) |
| | Other pattern | 18 (31.0) |
| | Referral only | 10 (17.2) |
| | N/A | 10 (17.2) |

Chart 12 - Input from professionals



Engagement & activities

Services were asked about the main areas their staff were helping the individual to develop:

Table 16

| Main Areas | n (%)* |
|---|-----------|
| Personal care | 40 (69.0) |
| Domestic skills | 37 (63.8) |
| Understanding illness | 35 (60.3) |
| Supporting challenging behaviour | 35 (60.3) |
| Coping with stress/distress | 45 (77.6) |
| Building/managing social relationships and networks | 39 (67.2) |
| Crisis management | 29 (50.0) |
| Management of forensic needs | 14 (24.1) |
| Recovery focused goals | 34 (58.6) |
| Community re-integration | 42 (72.4) |
| Other | 3 (5.2) |

^{*}there can be multiple areas so will add up to more than 58 & 100%

According to the services, 44 (75.9%) of individuals got a copy of their care plan, 10 (17.2%) did not and four (6.9%) did not answer.

Table 17 Frequency of structured care

| Structured Care | Frequency | n |
|------------------------------------|-----------|----|
| MDT | Weekly | 26 |
| | Monthly | 17 |
| | Other | 5 |
| 1:1 sessions with patient/carer | Weekly | 27 |
| | Monthly | 4 |
| | Other | 12 |
| Review of care plans | Weekly | 5 |
| | Monthly | 36 |
| | Other | 5 |
| Community meetings | Weekly | 11 |
| | Monthly | 14 |
| | Other | 11 |
| Outings | Weekly | 24 |
| | Other | 19 |
| Psycholgical/psychosocial sessions | Weekly | 29 |
| | Other | 6 |
| Education about their illness | Weekly | 10 |
| | Monthly | 3 |
| | Other | 13 |
| OT input | Weekly | 30 |
| | Monthly | 1 |
| | Other | 12 |
| Activities | Weekly | 27 |
| | Monthly | 1 |
| | Other | 16 |

Access to community resources

We asked about access to local community resources, and heard that for 39 people (67.2%) there was access, but for 16 (27.6%) people there was no current access permitted; for 3 files (5.1%) this information was missing.

Physical health and healthy lifestyle

When we reviewed whether physical health was being monitored, we found that there was evidence of health checks for 42 people (72.4%), 34 people (58.6%) had access to health screening, and 7 people (12.1%) required treatment for substance addiction.

Restrictions

The care files indicated that restrictions were in place for 46 people (79.3%), and we found specific risk assessment, such as START¹³ and HCR20¹⁴, along with care approaches that incorporated risk assessments, such as CPA¹⁵ and PBS¹⁶ in place for 29 people (50%). The remaining records did indicate there were care plans in place, but did not identify specific documentation for the risks noted below:

Table 18

| Restrictions | n (%)* |
|--|-----------|
| Locked doors | 47 (81.0) |
| Escorted time off ward | 48 (82.8) |
| Safety and security in the ward/service (searches/testing) | 27 (46.6) |
| Access to phone | 16 (27.6) |
| Access to social media | 13 (22.4) |
| Seclusion | 3 (5.1) |
| Any other restriction | 10 (17.2) |

^{*}there can be multiple restrictions so will add up to more than 58 & 100%

Chapter 3 summary

While it was not possible to fully compare the care and treatment people received before and after their transfer, we were able to gather a range of views about certain aspects. Most people told us that their care prior to transfer had not been that good, or was not good at all. Conversely, there were more people who told us that since their transfer, they now found their care to be very good or quite good since they had moved.

Overall, the views of the people that we met with and their relatives were mainly positive about the changes made possible since their transfer. We heard that for some individuals, there were more opportunities to engage more frequently with a wider group of professionals, and that access to activities in and out with their current environment was an improvement to that in the previous NHS Scotland facility. For the relatives, the majority were kept up-to-date and actively involved in decisions regarding their family member's care; the only area where there was a lack of activity was in discharge planning both for the individual and their relative.

While we found good engagement and participation with individuals in their recovery journey, there were still some concerns raised about maintaining progress, and ensuring that the skills acquired in their current setting could be transferred when the individual returned to an area closer to their families.

We recommend that:

4. NHS Boards who are funding an out of area placement should ensure development and incorporation of a structured plan with the independent healthcare provider that

¹³ START is the Short-Term Assessment of Risk and Treatability, developed in 2008

¹⁴ HCR-20 is the Historical Clinical Risk management 20 (v3) is the most commonly used forensic risk assessment in the UK

¹⁵ CPA is the Care Programme Approach is described as a framework for the delivery of mental health care, developed in England in 1991 and most commonly used in Scotland with people in forensic services.

¹⁶PBS is Positive Behavioural Support is a widely used and person-centred approach to identifying and meeting a person's support needs, most commonly used to support people with a learning disability

includes active rehabilitation and engagement back to the local area where the person will be returning to.

Chapter 4: Repatriation and/or the next steps

What we expected to find

At the time when a person's care is transferred out of the local area, we would expect there to be a focus on what needs to be put in place to support a return to the original geographical area. We would expect that the team of professionals involved, across health and social work/social care services, would develop key actions and outcomes to aid the person in their recovery; these actions would be measurable, achievable, realistic, targeting specific needs with clear timelines in place; resources and interventions would be clearly identified.

We would expect this plan to be inclusive and involve the individual, their relative/carer and that the discharge planning process begins at the earliest possible stage of the person's admission. There should be regular reviews of the discharge plan involving all of the key people, and at defined time intervals with focus on the objectives and goals to be achieved towards a positive discharge.

What we found

The views of those with lived experience

We wanted to know what people were aware of in relation to plans for their future, and specifically if they were going to return to their home health board area, or somewhere else. We were able to gather this for 40 individuals; there were 19 individuals where we could not/did not collect any details about repatriation as this was not a focus of their current care and treatment.

Chart 14 - Are individuals aware of plans for repatriation?

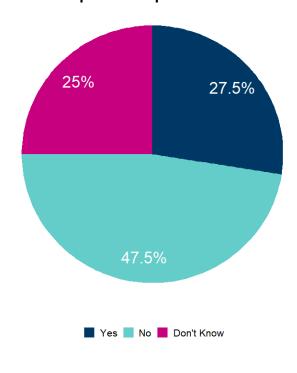


Table 19

| Activities relating to repatriation | Yes | No | Missing |
|---|-----------|-----------|-----------|
| Individuals involved regularly | 13 (22.0) | 3 (5.1) | 43 (72.9) |
| Given updates about returning to previous care setting | 5 (8.5) | 11 (18.6) | 43 (72.9) |
| Any specific goals they need to work towards | 12 (20.3) | 1 (1.7) | 46 (78.0) |
| Any difficulties with them returning | 7 (11.9) | 6 (10.2) | 46 (78.0) |
| Are their family/carers (if any) involved | 11 (18.6) | 3 (5.1) | 45 (76.3) |
| Do they see anyone from their previous service who discusses their ongoing care with them | 9 (15.3) | 4 (6.8) | 46 (78.0) |

Views from relatives

We asked if there had been an impact on relatives as a result of the out of area placement. 10 (83.3%) said it had had an impact, while two (16.7%) felt there had been no impact on them.

Some themes of concerns are noted below:

Chart 13 - Carers' views about the impact of the placement



We had some specific comments about the impact on the relative/family:

"His illness has impacted on us in many ways; it has impacted on all our family - my relationship as his mother, with his brother, who he does not have a relationship with. Having your son such a distance away, and having to travel such a distance to see him, there were no local services in nearby that could help us."

"There's an impact on relationships due to distance, travel time, and financial implications and cost."

"There has been a lot of worry and stress in the family, we have raised him and at times that was hard. He was a difficult young man, who got himself into lots of trouble."

We asked the relatives what the next steps should be.

For the individual:

One carer told us that they now feel that if their relative was nearer home he would have more community links and access to his family. The carer acknowledged that he would need a bespoke home (with some adaptations), with a specialist team who were suitably trained to support him.

"My wife and I do worry for the future."

In relation to the discharge plan:

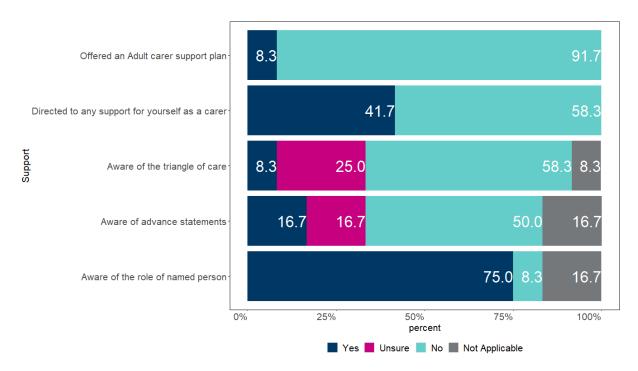
"There is a view that this service is a home for life."

"Yes there are ongoing discussions with [funding service]."

"Staff and psychiatrist does not [know] where or when. All very vague."

We also wanted to know about the support that was made available to carers.

Chart 14 - Carers' support



Other comments we heard were:

Our Commission officer said that "The carer has advocated for many years for him to be repatriated to Scotland... she feels that the service was initially helpful, but now her relative is at a point in his care when he could be at home in the right setting. This view was also supported by the clinical team when I met with them. She continues to battle for this, but it has been at a cost to her mental and physical health at times".

We were told that, "The communication with HSCP is poor at the current time. There's no supervision of guardianship. If something happened to us then it would be the local authority to take this on. We have spoken of finding alternative arrangements. No support from local HSCP."

"We are pleased with this move ... and are hopeful that in time [person's name] will be able to come back..., we think he may always need some kind of support to live in the community.

Current service providers' discharge planning activities

We asked the current service provider to identify the main barriers in relation to effective discharge planning.

Figure 2

planning kitchen environments impasse ongoing behaviours significant aggression notes specialist community others treatment provided high highland can present borders past planned within around placement due admitted progress additional **risk** made life move discharge needs also weight history services place service local could new mdt bespoke current home lack area health abuse difficult contact level regular issues poor mental back staff manage moving stability currently discussion appropriate still hospital challenging plans clinic behaviour discussions attempts violence seem finding restoration housing physical every suitable accommodation recently lothian impact

Comments provided by staff from the current service providers highlighted the lack of services in local areas, risks to the individual or others, and where the individual was not well enough to return to local area:

"Lack of forensic service in the home area which is the current barrier is moving back to that area."

"Issues with health board finding appropriate placement back in local area - discussions have lasted for six months."

"...has made significant progress but we are in a difficult position at the moment as there is an impasse in opinion as to where her future needs can be met."

We asked whether discharge planning was taking place. For approximately a third of individuals (n=19, 32.8%) there was but for 31 people (53.5%), there was no discharge planning, and this information was missing for 8 individuals (13.8%).

The funding service was involved in 23 cases and not in 13 cases; information was missing on 22 individuals.

Chart 15 - Type of funded service involvement

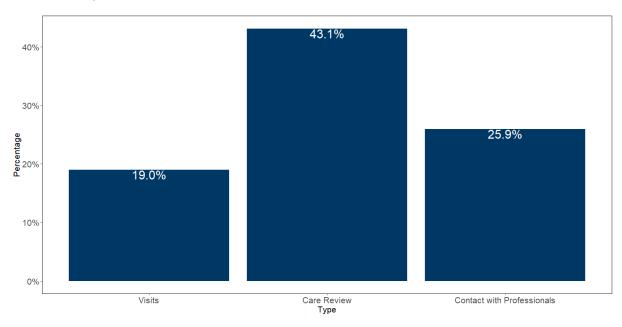


Chart 18 - Current service providers' reasons for lack of funding service involvement

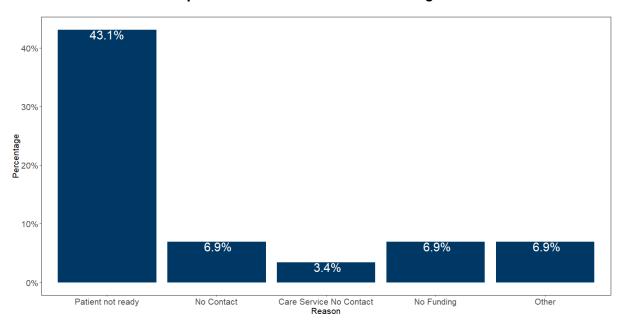


Chart 19 - Do current service providers have concerns about repatriation?

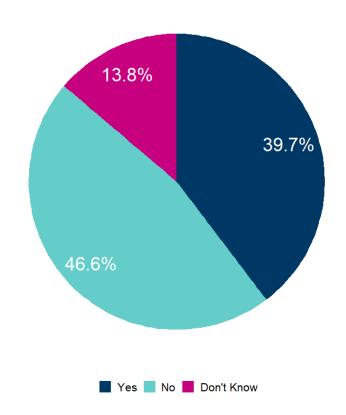
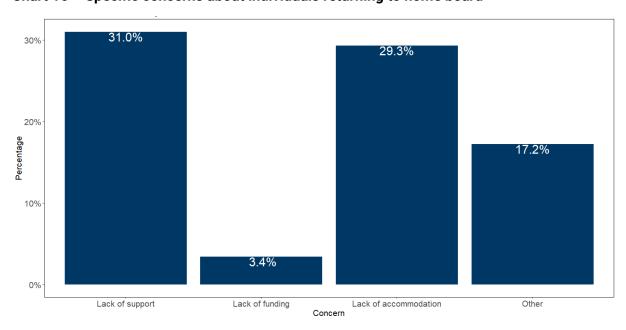
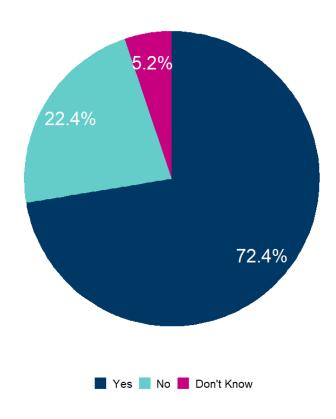


Chart 16 - Specific concerns about individuals returning to home board



We wanted to find out about the involvement of family and friends to support the discharge process.

Chart 17 - Are family and friends involved in supporting discharge?



Levels of involvement varied.

We were told about regular involvement:

"Frequent contact with mother and aunt, they support his trip to horse riding twice a month. Also carer comments that the service is in regular contact."

"... sister is his named person and also participates in his CPA meetings. Has daily contact with her brother by phone."

"Good contact with family who he phones regularly. Sees mother and father monthly and his sister visits every two months. The team are now progressing to home visits (escorted). They take him home leave him with his parents for a few hours then return to take him back to the clinic."

Some only have limited contact however:

"Only recent involvement since [being at location] with father and sister. Phone contact primarily, not clear if family have visited?"

"Card and cheque yearly from father but apart from that no personal contact."

"Mum and dad are welfare and financial guardians. Travelling for them can be challenging due to living four and five hours away."

For some, there was no contact:

"Family have severed contact."

"No living family"

"Does not wish parents to be involved currently."

Funding service involvement in discharge planning and repatriation

We asked what repatriation plans were in place for the individual's return, giving the following possible options:

Table 20

| Plans to support repatriation | n (%) |
|---|-------|
| Yes, repatriation required | 21 |
| Repatriation not required (still in active treatment) | 10 |
| Repatriation not agreed | 10 |
| Other | 9 |
| Missing information | 1 |

There were a number of reasons given as to why repatriation had not been agreed, and other issues were indicated that had prevented a return to the person's original board area. The main reason noted for a number of people was that they did not wish to return to their home area, while for others it was the lack of a local service, or the need for a specialist service that at this time has not been built, or even the lack of a service in Scotland. For a few, their physical and mental health care needs were still being met by the current services; for a number of people, engagement with the family and the home health board area was the other issue that was having an impact on repatriation. There were no placements for life noted for any of the individuals whose care we reviewed.

We asked if there were any barriers to repatriation:

Table 21

| Plans | n (%) |
|---------------------------|-----------|
| Legal issues | 2 (9.5) |
| Patient views | 0 (0.0) |
| Family/carer views | 1 (4.8) |
| Lack of service provision | 15 (71.4) |
| Lack of accommodation | 12 (57.1) |
| Other | 3 (14.3) |

The main barriers that were given related to a lack of a specialist service that would be able to meet the needs of the individual. The Coming Home ¹⁷ report highlighted that for a majority of the placements there was a need for specialist services rather than treatment in a more generalist setting. We found this to be the case in the majority of services that we visited too.

We asked what plans had been put in place to support the individual's return to the area. In 4 cases (7.8%) it was said there were clear plans in place, in 5 (9.8%) it was said the discharge meeting was still to take place, and for 13 people (25.5%) the return was agreed but no clear plan was in place. For 15 people (29.4%) other activities were taking place and for 14 people (27.5%) there was no information evidencing support of return to the original home board.

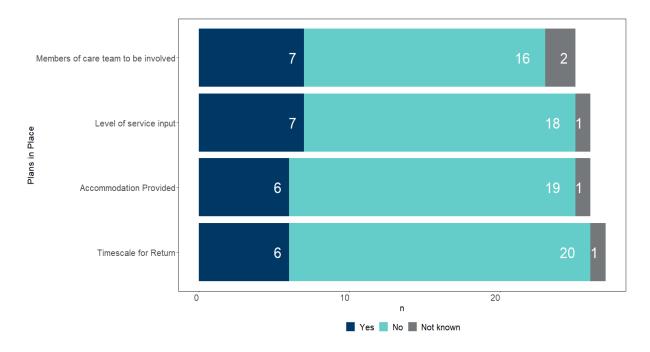
Where plans were in place, they included:

Table 22

| Plans in Place | | n |
|-------------------------------------|------------|----|
| Timescale for return | Yes | 6 |
| | No | 20 |
| | Don't Know | 1 |
| | Missing | 24 |
| Accommodation provided | Yes | 6 |
| | No | 19 |
| | Don't Know | 1 |
| | Missing | 25 |
| Level of service input | Yes | 7 |
| | No | 18 |
| | Don't Know | 1 |
| | Missing | 25 |
| Members of care team to be involved | Yes | 7 |
| | No | 16 |
| | Don't Know | 2 |
| | Missing | 26 |

¹⁷ Coming Home: A Report on Out-of-Area Placements and Delayed Discharge for People with Learning Disabilities and Complex Needs (www.gov.scot)

Chart 18 - Are plans in place to repatriate?



We asked if there were concerns about the individual returning to their home health board area. 38 (74.5%) of funding boards had concerns, 7 (13.7%) did not, and for 6 (11.8%) we did not have a response for this question. Concerns were generally around lack of appropriate service or risk of recovery being impacted due to being repatriated.

Figure 3



Chapter 4 summary

We found that, for most of the people that we were able to speak with about their plans for the future, whether that was returning to their home board area or somewhere else, they either did not know about this, or there were no plans in place. When we looked at activities in relation to repatriation, we found that much of this information was missing, people were not given regular updates, and were not fully informed about what some of the barriers to discharge were.

We heard from the relatives that there was little information given to them in their role as unpaid carers, and that the impact of travelling to see their family member, and the toll that this took on their relationship affected nearly all of the relatives that we spoke with.

For both the current service provider and the funding service, there was a common concern around effective discharge planning, however the reasons for this differed for each service. For the current provider, they identified that getting engagement from the funding health board could be challenging and slow; for the funding service, it was around their concerns relating to a lack of an appropriate local service, and the risk of relapse for the individual.

We found that with the discharge planning processes that were in place, there was nominal representation from the funding health board. At review meetings, the focus on goals and outcomes to achieve positive discharge were not well defined. Planning being undertaken by the funding health boards at a strategic level was not then shared either with the individual, their relative or the current service provider.

We recommend that:

5. NHS Boards develop and apply a set of discharge planning standards informed by cross agency multi-professional groups and those with experience (carers and people with experience of services) which focus on recovery and return to local areas.

Chapter 5: The impact and cost of out of area placements

What we expected to find

In 2018, the *Coming Home* report identified that for the individuals whose care was out of area, the impact of this could be life-changing. The report highlighted that there was also an impact on local services in that resources may not be targeted in developing the right services.

In sight and in mind (2020) reported that the Care Quality Commission estimated that more than two thirds of NHS England's budget for in-patient mental health rehabilitation was spent on out of area placements; this equated to around £350 million. More recently, the media have published findings that the cost to NHS Scotland for sending people to specialist services in England over a five-year period, including those for complex surgeries and mental health, was nearly £50 million.

We expected to hear that health boards were spending budgets out of area to ensure the provision of treatment, which should not be refused or delayed because of a lack of local provision, and that this, in turn, may result in significant financial cost as well as a cost related to the wellbeing of their patients and those important to them.

What we found

We asked if there had been any concerns/changes, in relation to a person's mental state and behaviours, as a result of the transfer to the service. 22 (43.1%) of the professionals that we spoke with said there had been no concerns or changes; five (9.8%) did not comment.

24 (47.1%) said there had been concerns, identifying these as:

Table 24 – Concerns/changes in relation to transfer

| Concerns/changes | n (%)* |
|---|-----------|
| Deterioration in individual (e.g. mental state/behaviour) | 11 (21.6) |
| More intensive input has been required from health care professionals e.g increased staffing, continuous intervention | 14 (27.5) |
| Loss of contact with family/friends community | 14 (27.5) |
| Any other concerns | 11 (21.6) |

^{*}there can be multiple concerns so these are not mutually exclusive

Some of the comments from the professionals in the services funding the out of area care acknowledged the challenge for a service in providing care for the individual:

"There has been less challenging behaviour or incidents. Within two weeks of a move, his behaviours settled as there were very few incidents compared to previous placement. No restraints have been used compared to his time in supported living."

and

Dr A noted that "This is the best I have ever seen her. This appears to be due to either to the service or the fact that she is in a stable place for a prolonged period, which is positive to note."

However, some of the points made to us indicated there were mixed views and concerns:

"There's been a history of constant observations in unit. There have been concerns noted regarding the relationship with RMO and potential institutionalised behaviour due to period in placement. Despite this there's been positive work with psychology and OT."

and

"There's a lack of direction in placement or rehab pathway. As a health board, we have had issues with getting a handle on what the unit are saying. There's no communication with new RMO despite attempts. We have concerns about levels of freedom and restrictions, in particular 2:1 which appears to be in place and will never stop."

We asked about whether the funding service considered the person to still be in active treatment, 44 (86.3%) said that this was the case, while 7 (13.7%) said the person was not. Of those who were not in active treatment, we asked what needed to be put in place for discharge or transfer:

"There is the view that he is still in active treatment and although there is clarity on what he may need in the future, there appears to be no active work being undertaken".

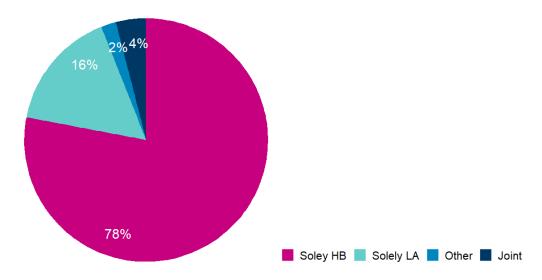
"The health board believes there is a need for an active plan to move on but is not forthcoming from the unit. There is no clear plan of what would happen next from leaving the unit".

"There have been discussions about moving her to a step-down service, although this would be in the local area and agreed and organised with SW".

We asked if there were concerns about the individual returning to their home health board area, 38 (74.5%) of funding boards had concerns, seven (13.7%) did not, and six (11.8%) did not provide any additional comment about the question. Concerns were generally around lack of appropriate service or risk of recovery being impacted due to being repatriated.

We asked about how the funding was provided, whether this was solely health board funded, jointly funded or through other funding sources (Chart 24).

Chart 23 – Funding source



We found that for 40 (78%) people, the funding came directly from the originating health board, with a further eight (16%) placements being paid for jointly by health and social care/social work. For the remaining three individuals, their funding came from either NSD or the local authority due to the service that the individual had been supported in prior to transfer.

We then asked about the cost per year. We broke this down into categories as follows:

- Less than 100K
- 100 to 200K
- 200 to 300K
- 300 to 400K
- 400 to 500K
- More than 500K
- No information about annual cost
- Other

For the 59 individuals care that we had reviewed, we were able to obtain information for 43. For the 16 where the data was missing, this was due to either being unable to identify the responsible commissioning officer for the funding (n=8), or where we had identified a local contact, we did not receive the information about the cost of care as requested (n=8). We found that there were difficulties in getting the final cost when we had contact with the local area social worker; they then needed to access the information about funding from the health service professionals which created delays in obtaining the full cost.

We also had costs given to us at a daily rate, costs that were reduced because of "block bed booking" additional costs that would be charged if there were additional requirements such as one-to-one observations and some funding services told us that there were likely to be increases on a annual basis to cover increasing costs.

The table below sets out the health boards and the costs associated with their funding of out of area placements, and where there is missing data:

Table 5

| NHS Board | <100K | 1-200K | 2-300K | 3-400K | 4-500K | 500K+ | Missing |
|--|-------|--------|--------|--------|--------|-------|---------|
| Ayrshire & Arran | - | - | 2 | - | - | - | 0 |
| Borders | - | 2 | 1 | 1 | - | - | 1 |
| Dumfries & Galloway | - | 1 | - | - | - | - | 2 |
| Fife | - | 1 | - | - | - | - | 2 |
| Forth Valley | - | - | - | - | - | 1 | 0 |
| Grampian | - | 1 | 5 | 1 | - | - | 1 |
| Greater Glasgow & Clyde | - | 2 | - | - | - | 1 | 2 |
| Highland | - | 1 | 3 | 1 | - | 2 | 3 |
| Lanarkshire | - | 1 | 3 | - | - | - | 1 |
| Lothian | - | 4 | 7 | - | - | - | 2 |
| Tayside | - | 1 | - | - | - | - | 1 |
| Island boards including Western Isles, Orkney and Shetland | | 1 | - | 1 | - | - | 0 |

For some packages of care, they were at the lower end of the 000s, for some, they were at the higher end. For this reason, we took the costs at the mid point of the range of each 000 as an average. It should be noted that these costs are likely to be conservative, they only represent 51 individuals, and there may be people in out of area placements who were not identified in the census report, or from the data that we gathered (Chart 25).

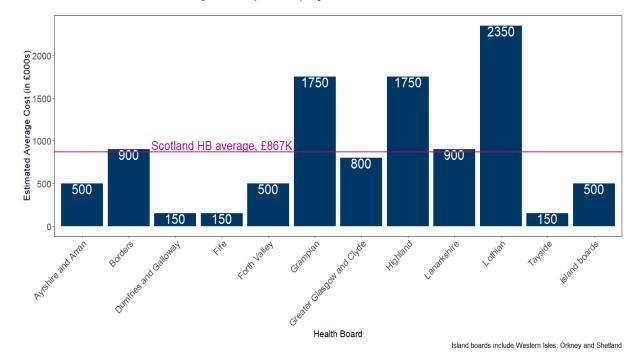


Chart 19 - Estimated average cost (£000K) by health board

There were no out of area costs that were less than £100,000 and there were three that were over £700,000, with these higher costs associated with funding additional staff to provide a higher level of observation.

The total cost for out of area care, where we had detail provided, was around £10,750,000. Where there were missing costs, we used a conservative approximate cost of £150,000 for the annual cost; this added a further £2,400,000, bringing the overall amount to approximately £13,150,000 for the 59 individuals.

We think this is an underestimate of the actual costs that health boards are paying.

Census data ¹⁸ found that for patients receiving care and treatment in NHS Scotland facilities, they had an average length of stay that was less than five months; for those who were in an out of area placement, it was an average of three years and eight months. If we use this average timescale, albeit 24 individuals' care that we reviewed had been receiving out of area care from anywhere between six and 15 years, an approximate cost to NHS Scotland is over £48 million for this sample.

59

¹⁸ https://www.gov.scot/binaries/content/documents/govscot/publications/statistics/2022/12/inpatient-census-2022-part-1-mental-health-learning-disability-inpatient-bed-census-part-2-out-scotland-nhs-placements/documents/inpatient-census-2022/inpatient-census-2022/govscot%3Adocument/inpatient-census-2022.pdf

Chapter 5 summary

We found that while the out of area placements were able to provide stability and did have a positive impact on the individual's health and wellbeing, there were difficulties identified by those services funding the care from a distance. These included challenges regarding effective communication between the funder and the care provider, opportunities for future planning and how the funding service could develop and resource a service for the individual back in their own health board area.

With nearly three quarters of the funding for placements coming from health, we found that even where there were integrated approaches to monitoring and support of the individual, there was also a lack of shared knowledge about discharge plans and the funding in place. At times, it was difficult to identify who was the responsible commissioner for a funded placement out of area, and gathering data on this was problematic.

When we were able to get an overview of the cost per placement, we were advised that there were different ways of reporting on this, and there was broad variation across health boards in relation to what was being charged. Some of the out of area services had additional costs relating to supervision and support of the individual, and most funding services that we spoke with anticipated that these costs would increase in this financial year. We were able to see that for two boards in the north of Scotland, there was an annual approximate cost of £4,000,000 for out of area placements, and this is likely to be an underestimate, that doesn't include the cost for the surrounding island communities. It could be suggested that this information evidences the potential to consider a more regional service that could reduce the funding cost, and the impact on individuals and their relatives/carers having to travel so far to receive care and treatment and maintain contact and critical relationships with each other.

We recommend that:

- Scottish Government review the monitoring of the funding costs for out of area placements and sit this with a national organisation such as NHS National Service Scotland, through the National Services Division, for centralised oversight and scrutiny.
- Scottish Government consider a human rights and health economics based approach as to whether a regional unit should be developed for those individuals who are considered at greatest risk of being out of area.

Conclusion

At the outset, gathering the data for this group of people was a challenge. We had expected the process to be relatively straightforward, and by using the Scottish Government 2022 census data, we expected to have a baseline, with some minor changes. What we found was a system that was difficult to access, as different key staff in NHS Scotland were responsible for gathering, collating and submitting the data to the Health and Social Care Analysis Unit for Scottish Government. The data submitted by NHS Scotland health boards to the unit in April 2022, differed – and in some cases there were significant differences - from the information we collected in November 2022 as part of our themed work.

Having obtained the information from key staff, and for some boards we were required to send evidence of the Commission's authority to access this, we collected this through contact with various departments/services in health boards. In the case of five health board areas, we did not receive accurate data; after obtaining information about some individuals from the private/independent healthcare provider, and through our follow up processes, we identified some individuals that may not have been in the 2022 census data, and who were not identified when we contacted the health boards.

We set out to describe this group of people who are, in some cases, hundreds of miles from the home board area, and their family. The 2022 census provides a range of demographic and diagnostic details; we wanted to expand on these, and gather additional and more in-depth data on length of stay, cost, and plans for repatriation. However, the key focus for the Commission was the views and opinions of those individuals who had been transferred out of the home board area, and wherever possible, we wanted to hear from their relatives/carers.

What we found was that for the group of people, who are known to have challenging behaviour, and who have had to move out of their home NHS health board area in Scotland, to a private or independent health care provider, the transfer has for the most part been a positive experience. We heard similar views from relatives. We had asked about care prior to transfer, and for nearly all of the group, they had spent long periods of time in NHS facilities that did not meet their needs; many had been in intensive psychiatric care units, with levels of restriction that would not have been helpful in promoting or supporting recovery.

What we also heard from those individuals and some relatives was that for most, being away from their family was not helpful, and that returning to their local area was the preferred option for nearly all those we spoke with. We found that for more than half of the group of people we reviewed (n=36), the average length of stay was 8 years.

While it was positive to hear that people were accessing treatment and therapy in their out of area placement, we also heard that there was very little focus on planning for their discharge, or return to either their home board area, or another NHS Scotland health care facility. We were reassured to find that while there was ongoing contact from key staff from the specific health board and/or health and social care partnership (HSCP), the focus of contact was mainly to visit the individuals, review their ongoing care and treatment under Mental Health Act legislation (for both Scotland and England), and to be the link or responsible professional monitoring the placement. We were disappointed to see a lack of an inclusive, solution focussed approach to repatriation and formal discharge planning.

The final chapter of this report considered financial cost. In recent times, there have been reports (*Coming Home*) and a media focus on the cost of care. There have also been UK Parliament bills that have debated, not only some of the hugely concerning aspects of care when individuals have been placed out of area (higher levels of restraint, the frequent use of seclusion, trauma and abuse) but also the cost to health services in both NHS Scotland and NHS England. Through this piece of themed work, we have given a very conservative figure of £13 million in relation to the out of area care we considered, but if the number of people who are placed out of area is not accurate (given the challenges we faced gathering this information) and if the average length of stay in an out of area placement is eight years, with the majority of these placements costing between £200,000 to £300,000 (n=21 per year), then we calculate the average cost for NHS health boards, per person, over that period could be approximately £2,000,000.

There is clearly an opportunity to take a national approach to out of area placements in order to use these significant funds to develop and create innovative solutions to the care and treatment of those people with the most complex needs more locally, with carers and relatives as active participants included in dynamic care and discharge planning processes.

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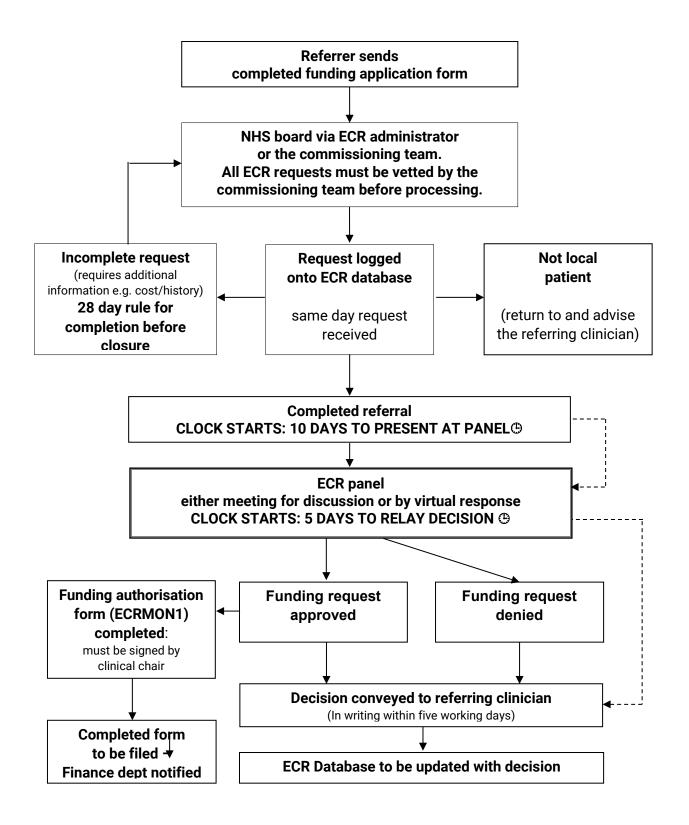
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Appendix 1 – Flowchart of extra-contractual referral (ECR) procedure





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