The Experience of Patients in the Royal Edinburgh Hospital – The Second Report

YOUR HOSPITAL   YOUR VIEWS   YOUR VOICE

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Executive Summary

Background & Purpose

The Royal Edinburgh Hospital (REH) Patients Council is a patient-led independent advocacy project providing independent collective advocacy to patients in the hospital. In 2019 the Patients Council received additional funding to do additional work researching the experience of patients in the hospital. 11 wards participated in the patient experience project – 5 Adult Acute wards (including IPCU), 4 adult Rehab wards, and 2 Older Person's wards. The project was conducted between November 2019 – September 2020. This report captures what patients shared about their experiences in the hospital. The project was led by Mark Somerville, the Patient Experience worker at the Patients Council, with support from the volunteers of the Patients Council.

Methods

The project utilized a mixed-methods approach drawing on multiple means of data collection. Quantitative data on the experience of patients was gathered through a 15-question Likert-scale survey. A total of 70 surveys were completed by patients across the hospital. The survey was designed by the Patient Experience worker in consultation with members of the Patients Council. Questions were developed from the previous Patient Experience project and consultation of issue logs from the Patients Council group advocacy meetings. Patients could complete the survey on their own, or with help from the Patient Experience worker or a member of staff. The survey also allowed space for patients to write additional comments in their own words. Qualitative data was gathered through 'feedback events', informal focus groups held on the wards of the hospital. The feedback events gave patients the opportunity to share their experience of being a patient in the hospital in their own words. 11 feedback events were held, and 58 patients participated. Thematic analysis was used to analyse the collected qualitative data.

The project further adopted a human rights framework to facilitate the quantitative and qualitative data analysis. The framework identifies how human rights are relevant to the various experiences shared by patients, areas in which these rights are potentially violated, and what is necessary for the hospital to employ a fully rights-based approach to service delivery. The human rights framework used for this purpose is primarily informed by the United Nations Convention on the Rights of Persons with Disabilities (CRPD), but also draws on the Patients Rights (Scotland) Act (2011) and the Mental Health (Care and Treatment) (Scotland) Act (2003).

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Key Findings

- Patients expressed a strong preference for an approach to treatment which prioritises the rights, will, and preferences of patients. Patients reported that being involved in their own care and treatment significantly benefits recovery, while not being involved causes significant distress and frustration.

- Patients report mixed experiences on the level of involvement they have in their own care and treatment. Many patients do report feeling supported to be involved in their own care and treatment, saying that they are involved in decision-making and the development of their care plan. However, a large number of patients shared that they are not supported to be involved, and that the treatment they receive does not reflect their will and preferences.

- Access to information is essential for patients to be involved in their own care and treatment, however many patients reported not having access to information they are entitled to. The side-effects of medication, your own care plan, human rights, and the pathway to discharge were identified by patients as the most important topics they needed more information regarding.

- Access to psychological therapies and the clinical psychology service was considered to be one of the most important resources available in the hospital. Patients expressed that psychology offered unique benefits to their recovery and wellbeing not afforded by a purely medical model of treatment, and the meaning-making process of psychology was of vital importance.

- Many patients throughout the hospital reported a lack of access to psychological therapies and the clinical psychology service despite believing it would be helpful. Inadequate access was particularly prevalent in the Acute and Older Persons wards.

- Patients reported that the art and music therapies available in the hospital, including the Artlink programme, were highly valuable to their wellbeing and recovery.

- The majority of patients reported that their experience in the hospital was positive and that the hospital was a helpful place for them to be. Many patients shared that they felt they had made significant progress in their recovery while in hospital. The majority of patients also reported that they felt the hospital was a safe place.

- Patients identified several aspects of being in hospital which caused significant distress and had the potential of causing trauma or re-traumatisation. Excessive restrictions, seclusion, non-consensual or coercive treatment, poor treatment from staff, and the use of restraint were issues identified by patients as having severe consequences for their wellbeing and inhibiting recovery.

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- A history of trauma is highly prevalent in people with mental health problems. It is essential for the hospital to adopt an explicit trauma-informed approach to all aspects of care and treatment to provide the highest standard of care to all patients.

- Patients identified that there was an ideal length of time to be in hospital. Staying in hospital for too long threatens to undo the progress patients have made in their recovery and can be just as damaging to their wellbeing as being discharged too early.

- Many patients described problems with the discharge process. The major problems for patients were not being involved in discharge planning, not knowing what they had to do to be discharged, and a lack of support during discharge. Leaving hospital is a very vulnerable time for patients, and these problems threaten to undermine the progress patients have made.

- Accommodation was identified as a significant issue for many patients when transitioning from the hospital back into the community. Several patients recounted experiences of being discharged into unsafe and unsuitable environments, saying that these negative experiences directly led to their being readmitted into hospital.

- Patients reported that there is little continuity of care between hospital and community, which leaves patients lacking support after leaving hospital.

- The relationships patients have with staff is a very important determinant of the overall quality of the patient experience, and the overwhelming majority of patients reported very positive views of staff. Patients described staff as kind, respectful, compassionate, and empathetic. Nurses were described by many patients as very hardworking and dedicated to supporting patients.

- Patients discussed the importance of person-centred care and treatment, sharing that being seen as an individual with unique needs significantly improves the quality of care they experience.

- Many patients shared that they feel they aren't treated as a person first, but rather they are labelled and judged based on their diagnosis or the first impression they made. These labels and judgements were said to be dehumanizing and very difficult to overcome regardless of how much progress a patient makes.

- Loneliness is a very common experience for many patients in the hospital. This is a long-standing problem which was also identified by the previous patient experience project. Some patients shared that loneliness and social isolation was the most difficult part of being in hospital. Other patients also discussed the importance of the relationships they had made with staff and other patients, identifying that social relationships were very important to their wellbeing and recovery.

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Recommendations

The results of the Patient Experience project have provided a rich and nuanced account of what it is like to be a patient in the Royal Edinburgh Hospital. The Patients Council has developed the following list of recommendations based on the experience patients have shared throughout the project. All the recommendations made have the backing of a strong patient mandate and are in line with a human-rights based approach to care and treatment.

1. The hospital should embrace a human rights-based approach to care and treatment and aim to be fully compliant with the United Nations Convention on the Rights of Persons with Disabilities. In line with this, the hospital should shift towards a model of 'supported decision-making' and away from the practice of 'substituted decision-making'.

2. The hospital should adopt a rigorous trauma-informed approach across all levels of care. This should include an evaluation of current hospital policy regarding the use of restraint, restrictions, and non-consensual treatment, and the training of all staff in trauma-informed care.

3. The hospital should aim to involve patients as much as possible in developing their own care plan, and in making decisions about their own care and treatment. Decisions should be made with patients, rather than being made for them, and the treatment patients receive should reflect their own will and preferences as much as possible and prioritise their human rights.

4. Patients should be better informed about what's happening on the ward and have access to all the information they require. This includes general information about the ward and staff, and also specific information about their own care and treatment plan. This is an essential step to empower patients to be involved in their own care and treatment, as patients cannot meaningfully participate in decision-making without being adequately informed.

5. It is crucial that all patients, whether they are detained or in the hospital voluntarily, are fully informed about their legal and human rights and are aware of how to exercise these rights. This should be proactively offered to patients rather than waiting for patients to ask for the information.

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6. The provision of psychological therapies across the hospital should be substantially increased to meet the patient demand and address the lack of access reported by many patients. This is a necessary and essential step to improve the patient experience and the standard of care in the hospital. The services of the clinical psychology team should be proactively offered to patients to ensure that all patients know what services and treatment options are available in the hospital.

7. Art and music therapy in the hospital is very highly valued by patients and so these services should be maintained and expanded upon. Both individual sessions and group sessions should be made available to patients.

8. There should be a clearer route to discharge, and patients should be made more aware of what they must do to move on from hospital. Patients should be fully involved in the discharge planning process to make sure they feel prepared to leave, including visiting their future accommodation. The experiences of patients who are readmitted to hospital after being discharged should be explored to identify how the discharge process can be improved to support patients to maintain their recovery after leaving hospital.

9. Attention should be paid to the issue of loneliness in the hospital. Many patients report feeling lonely and socially isolated, and this has a strong negative effect on people. Social interaction is very important for people in hospital and more should be done to help patients socialise. Increased group activities on the ward and staff engagement with patients are important first steps to tackling this issue.

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Background

The Royal Edinburgh Hospital (REH) Patients Council is a patient-led independent advocacy project providing independent collective advocacy to patients in the hospital. In 2018 the Patients Council received funding to do additional work researching the experience of patients in the hospital between the period of October 2018 – May 2019 as a Quality Improvement project. The Patients Council gathered information from patients on 7 wards of the hospital – 2 Adult Acute wards, 2 Adult Rehab wards, and 3 Older Persons wards. A report on the project entitled "Strengthening the Patient Voice" was produced and published in May 2019.

In 2019 the Patients Council received additional funding to continue and expand the Patient Experience research project. 11 wards participated in the second phase of the project – 5 Adult Acute wards (including IPCU), 4 adult Rehab wards, and 2 Older Person's wards. The project was conducted between November 2019 – September 2020. This report captures what patients shared about their experiences in the hospital. The project was led by Mark Somerville, the Patient Experience worker at the Patients Council, with support from the volunteers of the Patients Council.

The Patients Council would like to thank every patient who took the time to share their experiences and views. The contributions of every patient were invaluable. It is the hope of the Patients Council that the experiences, thoughts, and feelings shared by patients throughout this report can be used to provide guidance for projects aiming to improve the patient experience.

The Patients Council would further like to thank the nurses on the ward who supported patients to complete the surveys and raised interest in the feedback events. The recreation nurses in particular made a significant impact in increasing engagement with the project on the ward.

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Methods & Analysis

Information was gathered through two means – a survey instrument (see Appendix 1), and a focus group style 'feedback event'. Two means of data collection were utilised as the previous phase of the Patient Experience project identified that patients differed in their preferences for how they wanted to provide feedback on their experience on the ward. The data was gathered between the period of January 2020 – August 2020. The majority of feedback events were held pre-Covid, with the exception of the feedback event on North Wing which was held in August. 70 patients completed surveys and 57 patients participated in the feedback events. The table below shows the breakdown of survey responses and participation in the feedback events across wards. Thematic analysis was used to identify patterns across the qualitative data collected from both the surveys and feedback events and group data under overarching themes.

Breakdown of patient participation across the different wards of the hospital

	Acute	Rehab	Older Persons
Survey respondents	43	19	8
Feedback event participants	25	23	9

The Survey

The survey consisted of 15 Likert-scale questions, and three open-response qualitative questions. Survey respondents were also offered space to leave additional comments under each Likert-scale question. The number of questions included in the survey was increased from the previous Patient Experience project, as it was identified that the vast majority of patients completed every question on the previous survey within a brief amount of time. It was thus felt that increasing the number of questions could allow for a greater level of data to be collected, while remaining accessible to patients.

The survey was designed to assess the major topics of importance affecting the patient experience as identified by the patients themselves. Questions were chosen to be included on the survey through four means. First, several questions were held over from the original Patient Experience project, although the specific wording of some questions were changed. Second, questions were developed to address significant points of discussion raised by patients in the feedback events of the previous Patient Experience project. Third, the issue logs of the group advocacy meetings held by the Patients Council across the hospital over the preceding year were scrutinised. Questions were then developed to address frequent or significant issues raised by patients which were not addressed by existing questions. The

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initial list of questions was then discussed with volunteers of the Patients Council and the wording was refined to make the questions clear and unambiguous. The final draft of the questionnaire was approved by the Management Committee of the Patients Council and was judged to effectively capture the topics of most importance to patients.

Respondents were given the option of completing the survey on their own, with a member of the Patients Council, a staff member on the ward, or with a visitor/carer in their own time. Surveys were distributed to patients by the Patient Experience worker during scheduled visits to the ward. Additional surveys were also left with nurses on the ward for patients who did not meet with the Patient Experience Worker during the initial visit. During the week building up the to the Feedback Event a nurse on the ward was asked to distribute surveys to additional patients and collect any completed surveys. 70 surveys in total were completed, and 67 respondents answered every question.

The Feedback Event

The 'feedback event' was designed to allow patients the opportunity to talk about their experience of being in hospital in their own words. Optimal times for the event to be held were agreed with Senior Charge Nurses or Recreation Nurses to ensure that the event would not clash with other activities on the ward. The Patient Experience worker visited the ward in the week preceding the feedback event to let patients know about the event, distribute questionnaires to patients, and answer any questions. 58 patients participated in the feedback events.

Each feedback event lasted for between 90 minutes to two hours and was led by the Patient Experience Worker with the assistance of 1 – 2 volunteers from the Patients Council. The optimal length of the event was determined by the previous Patient Experience Project. The event took the form of an informal group discussion over coffee and chocolates held in a communal area of the ward, typically the dining area. Patients could choose to stay for the entire length of the event or come and go as they pleased.

Each group discussion would begin with the two qualitative questions from the survey – asking patients what was good about the ward, and what was bad about the ward. From this point, the discussion preceded naturally, and patients were free to lead the discussion and talk about what was important to them. When conversation slowed, prompting questions drawn from the topics covered in the survey were used to start new discussions.

Comments from the group discussion were recorded with permission from patients on post-it notes which were then placed on a large poster-paper that the group could see. These

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post-it notes were used as additional conversation prompts, as patients were asked for their perspective on issues that had been discussed and recorded. A number of patients additionally requested to complete the survey on the day of the feedback event and were supported to do so by a member of the Patients Council.

Data Analysis

Thematic analysis, following the approach developed by Braun and Clarke[1], was used to analyse the collected data. Qualitative analysis of data discussed in this report covered both the comments made in the feedback events, and the additional comments made in the surveys. Individual 'items' of data were defined as discrete statements provided in the surveys, and the statements recorded in post-it notes during the feedback events. A total of 924 discrete comments were analysed. All data analysis was conducted by the staff member in charge of the Patient Experience project.

The coding approach used was largely inductive, meaning that the analytic process began from the data, working bottom-up to identify patterns of meaning in the data, rather than imposing existing ideas. Codes were identified primarily on the semantic level, capturing the explicit thoughts and feelings expressed by participants. The entire dataset was coded exhaustively and systematically, with every individual item assigned a code and full attention given to every data item to ensure that the full breadth of the patient experience was captured.

Initial candidate themes capturing patterns of ideas across the dataset were developed through collating complementary codes together and developing mind-maps and visual representations to identify potential relationships between themes. These initial candidate themes were then reviewed through a reanalysis of the underlying codes and data items collated under each theme. This process of identifying potential themes, visually mapping relationships between themes, and reanalysing the underlying data was repeated several times to reach the final selection of themes. The relationships between themes, capturing how the experiences shared by patients in one aspect of their care are informed by other aspects, were analysed to identify the crucial factors shaping the overall patient experience. Each theme is supported by relevant extracts from the feedback events or qualitative comments from surveys, however these extracts should not be taken to be exhaustive of the only recorded comments comprising each theme. Quantitative data from the survey questions is reported alongside the most relevant theme, and the qualitative data is used to provide further insight into the survey answers.

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[1] Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. DOI: 10.1191/1478088706qp063oa

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Human Rights Framework

Following analysis and interpretation of each theme, the experiences discussed by patients will be considered through a human rights framework. This framework will identify how human rights are relevant to the various themes, areas in which these rights are potentially violated, and what is necessary for the hospital to employ a fully rights-based approach to service delivery. The human rights framework used for this purpose is primarily informed by the United Nations Convention on the Rights of Persons with Disabilities (CRPD).

The UK Government ratified and agreed to follow the CRPD in 2009. Through ratifying the CRPD, the UK government agreed to work towards the progressive realisation of the CRPD. This means the NHS is obligated to take steps immediately and in the future towards the fulfilment and protection of the rights within the CRPD. As stated in Article 1 of the CRPD, the purpose of the convention is to: "promote, protect, and ensure the full and equal enjoyment of all human rights and fundamental freedoms by all persons with disabilities, and to promote respect for their inherent dignity." The definition of disability under the CRPD includes anyone with physical, mental, intellectual, or sensory differences which, in interaction with various barriers, may hinder their full and effective participation in society on an equal basis with others, including persons with psychosocial disabilities. The Human Rights Counsel of the United Nations defines persons with psychosocial disabilities as: "persons who, regardless of self-identification or diagnosis of a mental health condition, face restrictions in the exercise of their rights and barriers to participation on the basis of an actual or perceived impairment". This expands the protection afforded by the CRPD beyond the bounds of the medical model and ensures that the rights of all patients are protected regardless of their diagnostic status.

The CRPD mandates abandoning models of care based on 'substituted decision-making', in which decisions are imposed upon patients, and developing a model of 'supported decision-making'. A supported decision-making model gives primacy to the will and preferences of patients, protecting their right to autonomy, and ensuring appropriate support is in place to enable patients to make decisions for themselves. Under the CRPD supported decision-making must be available to all, with a person's level of support needs or mode of communication not being a barrier to obtaining support in decision-making. The principles guiding the CRPD, outlined in Article 3, and the specific articles to be discussed during this report are presented below.

In additional to the CRPD, the human rights framework in this report also refers to the Patient Rights (Scotland) Act (2011) and the Mental Health (Care and Treatment) (Scotland) Act (2003).

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The General Principles Guiding the CRPD

Respect for the inherent dignity, individual autonomy including the freedom to make one's own choices, and independence of persons
Non-discrimination
Full and effective participation and inclusion in society
Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity
Equality of opportunity
Accessibility
Equality between men and women
Respect for the evolving capacities of children with disabilities and respect for the right of children with disabilities to preserve their identities

Member Checking

While an inductive approach was taken to coding, it should be noted that it is impossible to approach data without any preconceived ideas. It is inevitable that the process of analysis was influenced by the Patient Experience worker's pre-existing knowledge of the experience of patients in the hospital. To counter this bias, a process of member checking was undertaken to ensure that patients in the hospital agreed that the analysis accurately captured their experience. The process of member checking involved the Patient Experience Worker drafting a brief 'executive summary' of the final report. This executive summary included a broad overview of the analysis of the patient experience, and a series of suggestions to improve the patient experience. The Patient Experience worker then visited wards of the hospital to share the document with any interested patients and gather feedback. Patients were given the option to read through the document on their own and then share any feedback, or discuss it point-by-point with the Patient Experience worker. 4 wards were visited (2 Acute, 2 Rehab), and 9 patients gave feedback on the executive summary. All 9 patients who participated in the process of member checking approved the executive summary, agreeing that it accurately represented the patient experience, and that the suggestions would help patients.

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Theme 1: Collaborative and Patient-Led Care & Treatment

Throughout the hospital patients express a strong desire for a human-rights based approach to care and treatment which empowers and supports patients to make decisions regarding their own care and treatment. A human-rights based approach is patient-focused, patient-led, and prioritizes the rights, will, and preferences of patients. This approach is based on the principles of non-discrimination, treating patients as full and equal members of society, maximising independence, and a respect for the inherent dignity and autonomy of patients. This approach shifts the dynamics of care to a patient-led model in which patients and staff work collaboratively, rather than patients being passive recipients of care. Patients passionately argue that not only is it their right to receive a standard of care informed by these principles, but that it also supports recovery more so than traditional approaches. *Collaborative Care & Treatment* is an overarching theme encompassing the critical aspects of the patient experience of care and treatment in the hospital and how it conforms to these principles. This overarching theme is comprised of four themes which capture the barriers to patient empowerment, the violation and safeguarding of patient rights, and the difficult balance between restrictions and freedom. The four themes are *Patient Involvement, Access to Information, Restrictions,* and *Discrimination & Equality*
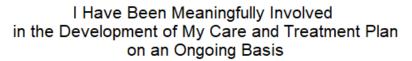
The central concept underpinning all four themes is patient empowerment and autonomy. Patients passionately discussed the importance of empowerment and the ability to act autonomously through taking control of their own recovery. Patients largely felt that while this may be possible in the hospital, there are many barriers that need to be overcome, and the hospital should better facilitate this goal.
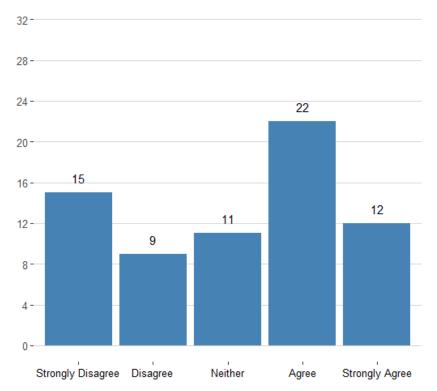
Patient Involvement

Empowering and supporting patients to take an active, decision-making role in their own care and treatment is a fundamental principle of any model of care informed by a modern understanding of human rights. *Patient Involvement* is a theme centred on this idea, concerning patients' experience of being involved in their own treatment, the development of care plans, patient autonomy, the barriers to collaborative care, and the detrimental effects of not being involved.

Two questions from the survey directly addressed the question of patient involvement. The results of these two questions were generally positive, with most patients reporting that they were involved in their own care and treatment. 34 patients (of 69 respondents) reported that they were meaningfully involved in the development of their care and treatment plan, while 24 patients reported not being involved. Similarly, 39 patients (of 69 respondents) reported that they were meaningfully involved in discussions and decisions being made about them, while 22 patients reported not being involved. These responses
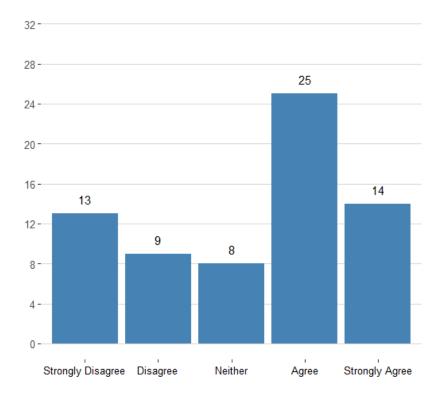
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reflect the diversity of experience in the hospital and demonstrate that while many patients are involved in their own care and treatment, a substantial number of patients are not. Patients are aware of this discrepancy in levels of involvement and suggested that different doctors have different approaches, with some being less likely to listen to patients and involve them in their own care. Patients also suggested that one's keyworker played an important role in facilitating patient involvement, commenting: "It's luck of the draw whether you get to be involved with your treatment" and "it depends on your keyworker".

I Have Been Meaningfully Involved in the Development of My Care and Treatment Plan on an Ongoing Basis

Response	Count
Strongly Disagree	15
Disagree	9
Neither	11
Agree	22
Strongly Agree	12

The level of involvement and autonomy that a patient has over their own care and treatment was a common point of discussion across all wards. Participants in the group discussions frequently cited involvement as one of the most important issues concerning patients, being an important determinant of a patient's quality of treatment and their hopes for recovery. Not being involved in your own care was seen as being a cause of distress, while having autonomy was seen as empowering and something which facilitates recovery. Patients said: "It's very stressful when I don't know what's happening", "It's distressing not being involved in decisions", and "Being given information and options empowers you to take control of your recovery".

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I Am Meaningfully Involved in the Discussions and Desicions Which Affect Me

In contrast to the more balanced and positive survey responses, the majority of discussions in the feedback groups on this theme identified level of patient involvement as a critical area which needs to be improved, with many patients not feeling involved. This lack of involvement was frequently experienced as both frustrating and highly detrimental to the quality of care received, and patients passionately expressed a need for change. Patients frequently described feelings of being powerless in their own care: "discussions are held behind closed doors", "doctors don't listen to me or respect my views", "I'm shut out and want to be involved", "My voice isn't heard". Multiple patients further stated that they felt bullied or coerced into accepting certain treatments. Power was felt to be consolidated in the hands of doctors, with patients having little recourse to challenge this authority, and this lack of autonomy undermined patient recovery.

Alongside these strongly negative experiences, examples of good practice were also identified. Patients discussed being supported to make decisions and working collaboratively with staff involved in their care: "we work together on changes to my care", "we discuss things together and I'm supported to make decisions".

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The emphasis on collaborative care in these examples of good practice highlights an important aspect of patient involvement expressed by patients. Being involved in your own care can be difficult, and staff should aim to actively support patients to do so. Several patients described their current experience of involvement as being highly demanding and requiring great persistence, with one stating "It's emotionally exhausting to persistently fight for yourself, you eventually give up asking". The idea of involvement being a "fight" was echoed by many patients, with others describing that patients who aren't capable of fighting will "slip through the cracks", "get ignored" or "fade away". There are also perceived risks to attempting to asserting yourself, with one patient commenting that "If you're outspoken you get punished". This creates a Catch-22 situation for some patients in which they feel that the consequences to trying to be involved are severe, but if they don't speak-up they'll receive inadequate treatment. This situation can result in patients being more resistant to treatment and less willing to engage with services.
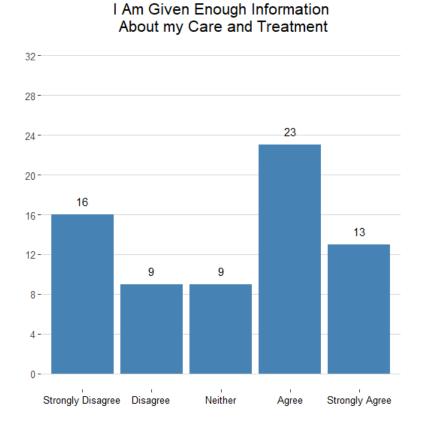
These comments illustrate that simply permitting patients to raise concerns or have a say in their own treatment is not sufficient, as this risks the dynamic of care becoming adversarial and seen as a "fight". Instead, a supportive environment must be established wherein patients are actively empowered to be collaborative partners and take an authoritative role in their own care and treatment.

Access to Information

The previous Patient Experience work argued that for patients to be empowered as active collaborators in their care, it was first necessary for patients to have access to all relevant information. *Access to Information* is a theme concerning this issue, encompassing whether patients feel they have adequate access to information, the circumstances under which information is provided or withheld, and the detrimental effects of being denied information. This theme is closely interwoven with theme of *Patient Involvement*, as the first step toward patient empowerment and involvement is for patients to have access to the information relevant to their own care and treatment. Information facilitates patient involvement by allowing patients to make informed decisions, while a lack of information prevents patients from being able to meaningfully engage in decision-making.

One question in the survey directly addressed the question of whether patients felt they were given enough information about their care and treatment. Responses to this question show that most patients feel they are given enough information about their care and

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treatment (N=36/70), but a substantial minority of patients do not feel adequately informed (N=25/70).

I Am Given Enough Information
About my Care and Treatment

This positive balance was not reflected in the additional comments made by patients in the survey and the group discussion, with the majority of comments being overtly negative. Patients spoke of not having enough information on a wide variety of issues including their own specific care-plan, the possible side-effects of medication, what their human rights were as patients in hospital, and more generally what's happening on the ward and the roles of different members of staff. A number of detained patients additionally stated that the reasons for their detention had not been made clear to them, and they were unaware of their specific rights as a detained patient. Throughout discussions on this theme, access to information was framed as being highly important and valuable to patients.

Knowledge of legal and human rights, for both detained and voluntary patients, is a critically important issue of safeguarding, and one patient stated that "[your rights] should be the first thing you learn about!". Without this knowledge patients are at an increased risk of their rights being violated. Making patients fully informed of their legal and human rights is the first necessary step towards empowering patients and developing an approach to care

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that prioritises the rights, will, and preferences of patients. Patients frequently spoke of how a lack of information caused them to feel "confused" and "unsure", and "frustrated", and perceived that they were being denied access to information they needed to know. One patient additionally reported that while information on their rights under the Mental Health Act had been conveyed to them, they found it to be too complicated and difficult to understand, so they didn't retain the information. This demonstrates that simply making information available may not be sufficient for all patients, rather it is necessary to ensure that this information is accessible and understandable to patients. When making decisions about patient care, staff should ensure that patients have full knowledge of their rights, rather than assuming this is the case, so that patients can make fully informed decisions. Patients commented that they often had to rely more on other patients for information than staff members.

While a small number of patients spoke positively about information access, it was also stated this was sometimes the result of patients repeatedly seeking out information, and it would be preferable for information to be shared proactively: "I am given information because I am asking for it – health care providers should facilitate more information sharing". Ideally, access to all information should be proactively offered to patients as a matter of standard practice, rather than patients having to ask. Patients praised staff who took the time to explain everything that they needed to know and answer any questions they had, however not all patients felt confident asking questions of staff. When the burden of requesting access to information is placed on patients, insecurity and uncertainty is created by unequal power dynamics. Patients may be unaware of what information they have a right to know and may fear reprisal for challenging staff.

To further facilitate information sharing, patients discussed the value of having access to written information and records of their own care and treatment. Written information provides a sense of security for patients, as it allows them to refer to previous discussions and decisions and have a certainty of what has already happened, and what will happen next. Patients having access to and control over information about themselves also helps to empower patients, as one patient stated: "When you have that [written records and your care plan] you can remember everything and know what's going on, and if they [staff] have something wrong you can tell them". The sharing of information benefits staff as well as patients, as it helps to ensure a shared understanding that facilitates a collaborative approach.
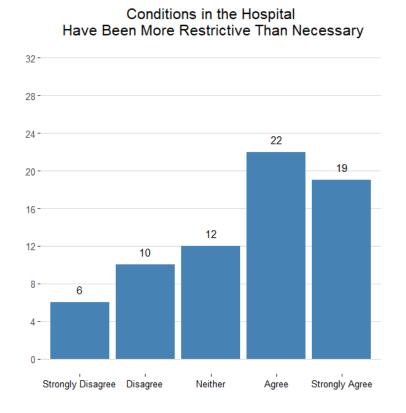
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Lack of access to information was framed as hindering recovery and moving on from hospital by several patients, with one commenting "There's no information and making progress on the route to discharge, I don't know what I need to do to leave", and another stating "There hasn't been any suggestions of future plans". The lack of a clear discharge plan is experienced by patients as disempowering, as it leaves them without a sense of control over their own recovery. It additionally negatively effects patient relationships with staff, as patients feel as though they are not being treated with respect, and instead "discussions are held behind closed doors" and "information is all kept secret". This ties into the theme of *Patient Involvement* in care and treatment. A lack of information access acts as a clear impediment to patients taking autonomy over their own care as patients must be well-informed in order to work collaboratively with staff and make decisions. Alongside patients not knowing about plans for discharge, a general lack of knowledge of one's own care plan was a particular issue for a large number of patients. Many patients reported that they had never even seen their care plan and had no idea what information was included in their care plan. Without access to this information, patients are left as passive recipients of care, rather than taking an active role. As outlined in the theme on *Patient Involvement*, this can have a severe detrimental effect on a patient's recovery, dynamics between staff and patients, and patient willingness to engage.

Increased access to information provides the ideal avenue to improve patient autonomy and engagement, as well as relationships with staff, allowing for a higher quality of care. It should be noted however that access to information alone isn't sufficient to empower patients, they must also be afforded the space and opportunities to act on this information and exercise their rights, will, and preferences. Many patients have well-informed views for how they want to be treated, but report that their views aren't meaningfully considered, an experience described by patients as very "frustrating" and "disrespectful". As such, *Involvement* and *Access to Information* are mutually dependent themes, with information necessary to facilitate involvement, and meaningful opportunities necessary to make use of this information.

Restrictions

The balance between freedom and restrictions in the hospital is an issue frequently raised by patients in the group advocacy meetings held by the Patients Council and throughout the Patient Experience project. Patients value their freedom and often feel that the restrictions imposed by the hospital are excessive and have an adverse effect on their recovery. *Restrictions* is a theme capturing how patients experience the hospital as a restrictive environment, issues related to passes, the effect of restrictions on treatment and recovery, and how patients view the appropriate balance between freedom and restrictions.

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One question in the survey directly addressed the question of restrictions in the hospital. The majority of patients (N = 41/69] stated that conditions in the hospital were more restrictive than necessary, while 16 respondents disagreed with this statement.

Conditions in the Hospital
Have Been More Restrictive Than Necessary

Strongly Disagree	Disagree	Neither	Agree	Strongly Agree
6	10	12	22	19

This view of the hospital being overly restrictive was reflected in the additional survey comments and group discussions, with the overwhelming majority of comments being highly negative. Patients discussed this topic passionately and identified it as being central to their fundamental human rights. The experience of being in hospital was described as "like being locked in a cage" and "feeling trapped and confined". A frequently used metaphor across different groups was the comparison of the hospital to a prison, with one patient further stating that they feel "staff treat me like a dangerous criminal".

Patients identified these restrictions as having a serious adverse effect on their experience in the hospital and their recovery, with several patients identifying restrictions as being the most difficult part of being in hospital. The damaging effects of restrictions are illuminated by the points raised in the theme of *Patient Involvement*. Patients discussed that the lack of autonomy over their own care and treatment was distressing and detrimental to their recovery. The lack of freedom experienced by patients due to the restrictive environment of the hospital exacerbates these feelings, undermining patient empowerment and the creation of a therapeutic environment conducive to recovery. Instead, many patients experience the hospital as feeling "authoritarian" and "like a prison". One patient

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eloquently described their life in hospital as follows: "I feel like a rare bird who has had her wings cut".

Excessive restrictions, including the use of compulsion, restraint, seclusion, and sedation were identified by patients as causing major distress and making patients feel vulnerable and unsafe: "I feel unsafe due to threats of injection and heavy sedation", "The more restrictive the environment, the more the patient suffers". Restraint specifically was identified as being not only distressing to experience but also distressing to witness happening to other patients, upsetting patients and creating an unsafe environment. The patient experience of restrictions in the hospital demonstrates the importance of a trauma-informed approach to care and treatment. Many patients in the hospital have a history of trauma, and it is possible for the hospital to re-traumatise patients if the treatment they receive resembles previous adverse events. The high level of distress patients directly associate with excessive restrictions speaks to the potential for restrictions to re-traumatise patients.
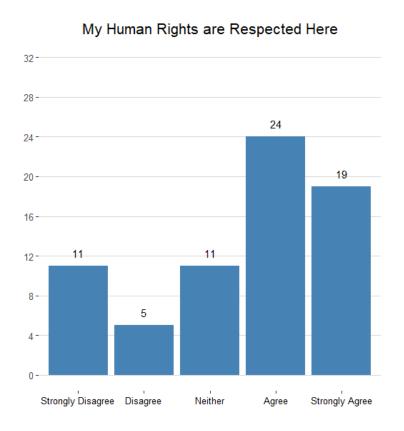
Lack of passes was specifically identified as a restriction that made being in hospital a more difficult experience. Patients expressed a significant amount of frustration at not being able to go out. A lack of passes contributed to a negative perception of the ward environment, as patients expressed that there's very-little do on the ward when you're inside all day, while being able to go into Morningside or the wider community is a valuable experience. The smoking policy is also experienced as frustrating by many patients, with this being a particular problem for patients who don't have passes to go out.

It is important to note that not all patients shared these feelings. In the survey 13 patients disagreed with the statement that the hospital was too restrictive, and a small number of patients expressed the feeling that the balance between freedoms and restrictions was appropriate. One patient stated that "restrictions are fair and judged individually", while another positively recounted that their level of restrictions have been matched to their progress in recovery "When I have been less well I was restricted in what I did, however this changed as I got better". Despite the overall negative view of restrictions, the majority of patients also viewed the hospital as a safe place which helped them to recover (See the *Recovery* and *Safety* themes). Patients additionally praised the good use of de-escalation techniques, and the decreasing use of restraint and sedation in the hospital. De-escalation techniques were felt to be a better approach, helping patients feel listened to, rather than punished. These comments also reflect the collaborative model of patient involvement preferred by patients discussed in the previous theme, with patients appreciating a model of care which empowers and treats them as individuals. In the experience of patients with a positive perception of restrictions, it seems that the balance of freedom is negotiated to fit the patient's unique recovery needs.
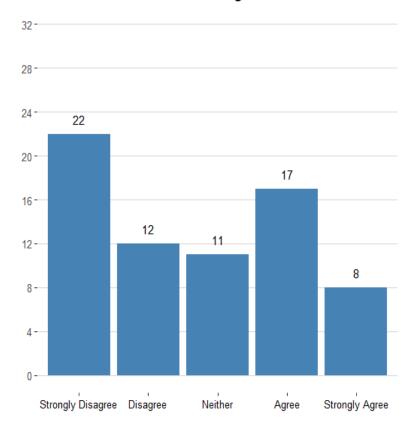
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Discrimination & Equality

While a human rights-based approach to mental health is increasingly recognised in legislation and policy, patients have long advocated for their fundamental rights to be recognised and respected. Throughout the history of the Patients Council, patients have frequently and passionately argued the necessity of prioritizing human rights in mental health services, and the severe consequences to patient wellbeing when these rights are violated. *Discrimination & Equality* is a theme capturing the patient experience of their human rights in the hospital. This theme covers patients' explicit perception of circumstances in which their rights are respected or violated, access to advocacy, problems with the tribunal service, discrimination in the hospital, and issues of accessibility and inclusion.

Two questions in the survey aimed to specifically explore the patient experience of their human rights in hospital. One question asked if patients felt their human rights were respected in hospital. Encouragingly the majority of patients (N = 43/70) responded positively, however a substantial minority (N = 16/70) responded feeling that their rights had not been respected, with 11 of these patients responding: "Strongly Disagree". A second question in the survey asked if patients had experienced discrimination while in the hospital. The answers to this question were more equally balanced, with 34 patients (of 70 respondents) saying they had not experienced discrimination, and 25 patients saying they had experienced discrimination.

My Human Rights are Respected Here

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I Have Felt Discriminated Against While Being Here

Qualitative comments on the survey and the group discussions provided more detail on the specific kinds of discrimination experienced by patients. Experiences of racial discrimination were described with one patient saying: "People who are white, English and from the UK get treated different which is completely wrong", and another patient reporting "I have been discriminated against for being Muslim from both staff and patients". Some patients spoke of feeling discriminated against specifically by their doctor, with one patient saying that this was due to her specific diagnosis: "Doctors stigmatise BPD symptoms; some disorders seem more socially acceptable than others". For other patients, their experiences of discrimination came from other patients and said that staff would helpfully intervene if they overheard. Incidents of sexism and discrimination for being overweight were also reported.

There is additionally an issue of discrimination regarding access to the clinical psychology service in the hospital. Patients on the Older Persons wards seemingly have significantly less access to the psychology service than the other wards of the hospital despite several patients on these wards reporting that they value psychology and would like access to this service. The unequal access to the psychology service appears to be discriminatory as these

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patients are being denied access to a service available elsewhere in the hospital on the basis of their age.

Comments on human rights were mixed. On the negative side, patients were very passionate, saying: "My human rights have been violated on every level" and "There's no freedom of speech". Other patients spoke more broadly of problems in the mental health system as a whole, saying "I strongly believe that the Mental Health Act of Scotland goes against human rights". Connecting to the theme of *Access to Information*, many patients were unsure of exactly what protected rights they have as patients in the hospital. This lack of information made it difficult for patients to stand up for themselves, as patients said that they didn't know when they had the right to make requests or challenge things that were happening to them. The Mental Health Act states that upon admission to hospital patients being detained should have their rights explained to them, but it is unclear if this happens consistently, or if these rights are explained in a way that is accessible to patients. Some patients report of only learning of their rights when talking to other patients or advocacy services. In order for patients' human rights to be safeguarded in hospital, it is essential that the patients themselves have reliable access to information about their rights and how to exercise these rights.

Several other patients spoke very positively of respect for human rights in the hospital, saying: "Blackford has been excellent at respecting human rights", "You are treated like everyone else", and "My human rights are completely respected". This demonstrates that there are examples of good practice in the hospital, and it is possible for care and treatment to be embedded in a human-rights based approach.

The tribunal service was specifically identified as a problem area by many patients who felt it was not respectful of their rights and worked against patients rather than safeguarding them. Specifically, it was said that "The tribunal process doesn't see the whole picture and doesn't take your circumstances into account". Multiple patients additionally told us of their tribunal reports being "full of inaccuracies and irrelevant information" that was used to restrict their freedoms. Challenging this inaccurate information was described as being exceedingly difficult, with patients having little recourse against what they considered to be an unfair judgement.

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The Mental Health Act states that all patients have a right to Independent Advocacy services, and access to advocacy was reported as being helpful in protecting patient rights. However, advocacy was described as being sometimes difficult to access, and patients expressed a need for increased access to advocacy: "Advocacy services are good at fighting for you but the tribunal and other services hinder them and don't work collaboratively", "There should be more advocates and increased access to advocacy". It may be that the provision of advocacy in the hospital needs to be increased to provide an appropriate level of safeguarding of human rights in line with the Mental Health Act. Alongside the importance of access to advocacy, patients also stated that they found value in being able to give feedback on their experiences: "There should be more things like this [referring to the Patient Experience project"].

Multiple patients with physical disabilities or mobility issues also spoke of problems they faced regarding accessibility. The hospital grounds were described as not being accessible to patients in wheelchairs due to the poor condition of the roads and pathways: "No physical access to the Hive and other hospital services because of my wheelchair and inaccessible roads and pathways". This was experienced as distressing by multiple patients, and the lack of accessibility was equated to discrimination as it meant disabled patients were disadvantaged compared to other patients and received unequal care and treatment. However, in the group discussions one wheelchair-using patient specifically noted that staff were very good at ensuring all outdoor outings were accessible to them. This may suggest that different wards are operating different policies for patients in wheelchairs regarding access to services.

Human Rights and Collaborative and Patient-Led Care & Treatment

The issues raised by patients in the themes under *Collaborative Care & Treatment* are relevant to a number of articles of the CRPD. Article 3 of the convention states that respect for individual autonomy and the freedom of people to make their own choices are core principles of the CRPD. Article 12 of the CRPD states that people with disabilities have equal recognition before the law. Article 25 states that people with disabilities have the right to access the highest available standard of health and treatment, and informed consent must be freely given prior to any treatment. Article 25 and Article 12 are interdependent – the highest standard of health and treatment cannot exist without respect for patient autonomy and their right to equal recognition before the law. Denial of patient autonomy and equal recognition violates patient wellbeing and negatively impacts the standard of care received

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as involving patients in their own care is known to improve the quality of care[2]. A large body of research additionally demonstrates that experiences of inequality and discrimination adversely affects mental health. Accordingly, for the highest standard of health and treatment to be achieved patient autonomy must be respected and patients must be involved as much as possible in their own treatment. Personalised care plans which patients are involved in creating and regularly reviewing are essential to ensuring this standard of care is being met.

Article 12 of the CRPD mandates a move away from substituted decision-making, and towards a model of supported decision-making. Retaining any model of substituted decision-making is in violation of the CRPD, as stated by the Committee on the Rights of Persons with Disabilities: "State parties' obligation to replace substitute decision-making regimes by supported decision-making requires both the abolition of substitute decision-making regimes and the development of supported decision-making alternatives. The development of supported decision-making systems in parallel with the maintenance of substitute decision-making regimes is not sufficient to comply with article 12 of the Convention.". The CRPD further states that supported decision-making should be made available to all, and a person's level of support needs or communication issues should not be a barrier to obtaining support in decision-making. This means there should be no justification for a patient not being involved in their own care and treatment and developing their own care plan.

Practices in the hospital which patients experience as distressing – such as restraint, excessive restrictions, and seclusion – are potential violations to Article 25 of the CRPD, as these practices do not represent the highest standard of care, but rather have an adverse effect on patients. A fully trauma-informed approach which aims to reduce any risk of re-traumatisation is necessary to be fully in line with Article 25.

Article 9 of the CRPD states that people must be provided with all of the information that they require, and steps should be taken to ensure that this information is clear, accessible, and understood. This means that patients should have full access to all information about their care and treatment, and staff should ensure that patients understand this information. Article 8 additionally states that awareness of the rights of people with disabilities must be promoted, and so it should be a priority for patients themselves to be made aware of their own rights. As full access to relevant information is necessary for patients to be involved in their own care and make decisions for themselves, the right to information is further protected under Articles 3 and 25.

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[2] Bombard, Y., Baker, G.R., Orlando, E. et al. Engaging patients to improve quality of care: a systematic review. Implementation Sci 13, 98 (2018). https://doi.org/10.1186/s13012-018-0784-z

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Article 5 of the CRPD states that all people with disabilities should be free from discrimination on the basis of said disability, and persons with disabilities must be guaranteed equal and effective protection against discrimination of all kinds. This mandates that the hospital must provide an environment totally free of any discrimination, and the experiences of discrimination reported by patients should be investigated as a priority. Article 9 additionally states that all people should have equal access to the physical environment, and barriers to accessibility, such as those described by patients using wheelchairs, must be eliminated. Article 3 further states that non-discrimination is a guiding principle of the CRPD. The inequality of access to psychological care experienced by patients on the Older Persons wards is discriminatory on the basis of age, and so is in violation of the principles guiding the CRPD.

The problems expressed by patients in regard to the tribunal process are potentially in violation of Articles 12 and 13 of the CRPD, which state that patients have the right to equal recognition before the law and effective access to justice. If patients perceive their tribunal as being unfair, there must be systems in place for judgements to be challenged, and patients must be supported to raise issues and complaints.

Under the Patient Rights Act and the Mental Health Act patients have the right to a care plan which is personalised to them, to be involved in the development of their care plan and be involved in regular reviews of their care plan. Patients additionally have the right to clear information about any medication they are prescribed and any other treatment they are receiving, and an explanation for why they need to be admitted to hospital. Sufficient information and support must be provided to enable patients to participate in their own care. Involving patients in their own care and granting patients access to the information necessary to be involved in decision-making are core principles of both the Patient Rights Act and the Mental Health Act. Under the Mental Health Act (2003) patients being detained additionally have the right to information about why they are being detained, how long they are being detained for, how to appeal this decision, and a clear explanation of their rights. Under the Mental Health Act (2003) all patients in hospital have a right to access independent advocacy services, including both individual advocacy and collective advocacy. The use of the minimum necessary level of restrictions is also a core principle of the Mental Health Act (2003). Additionally, a core principle of the Mental Health Act (2003) is that no patient or group of patients should be treated less favourably than other patients. The disparity in access to clinical psychology for older patients is in violation of this principle. The European Convention on Human Rights (ECHR) additionally provides protection for patient autonomy and legal capacity and these concepts have been developed further in ECHR case law.

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Theme 2: Treatment Options

Within a collaborative approach to care and treatment, it is necessary for patients to have access to a range of treatment options so as to ensure that their care plan reflects their will and preferences. Patients express that their treatment should not be restricted only to medication, but should also include psychological therapies, art therapy, music therapy, and other therapeutic activities which patients desire and find helpful. *Treatment Options* is an overarching theme comprised of three themes capturing patients experiencing of accessing a range of treatments, the barriers to accessing certain treatments, and the value patients ascribe to different types of treatment. The three themes are: *Clinical Psychology*, *Arts Therapies,* and *Medication*.
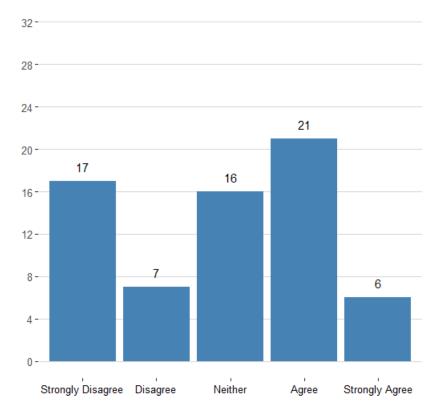
The central message underpinning all three themes is that patients value having access to multiple types of treatment and being able to exercise control and choice over their treatment options. Patients experience unique benefits from the different types of treatments, and strongly feel that having access to different treatments is superior to a one-size-fits-all approach reliant on one modality. However, there are many instances in which patients do not have access to different treatments, particularly psychological services, and patients feel this adversely effects their recovery.

Clinical Psychology

Psychological input is highly valued by many patients through the hospital, who consider psychology as offering substantial benefits to their care and treatment which are not available through a purely medical model of treatment. *Clinical Psychology* is a theme capturing the patient experience of psychological input, the availability of clinical psychology services in the hospital, patient awareness of these services, and the benefits of clinical psychology for patients.

The previous patient experience work identified that there was a variance in access to psychological input, with some patients speaking of not being able to access psychology when they needed it and others being unsure if it was available. To explore this further, one question in the survey asked patients if they had as much access to clinical psychology input as they would like. There was substantial variation in responses. 24 patients (of 67 respondents) indicated that they did not have their desired access to clinical psychology, while 27 patients were satisfied. The lack of access to psychological services appears to be a particular issue on the Acute wards and Older Persons wards. Across the acute wards of the hospital 39% of patients responded 'Disagree' or 'Strongly Disagree', compared to 22% of patients on Rehab wards, while 57% of patients on Older Persons wards responded 'Strongly Disagree'. No patients on the Older Persons wards responded positively to this survey question, with the remaining patients responding "Neither".

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I Have as Much Access to Psychological Therapy and Clinical Psychology as I Would Like

An analysis of qualitative comments on surveys further demonstrated that a substantial number of patients did not have desired access to psychological input and therapies. Several patients indicated that they had not had any input from the clinical psychology team, but that this was strongly desired: "I haven't had any access to psychology but I would want it, I think it would be more helpful than just my medication", "I haven't had any therapy at all despite asking for a referral several times". These experiences relate to the theme on *Patient Involvement*, suggesting that the care and treatment plans for these patients are not in line with their own preferences for psychological input. On the Older Persons wards of the hospital, it appears that there is little to no provision of clinical psychology or psychological therapies. This is despite several patients in these wards expressing a desire for access to psychological input, saying it would benefit them and it's something they knew they found helpful in the past. This appears to be an issue of discrimination, as these patients are being denied access to the clinical psychology service available elsewhere in the hospital on the basis of their age.

Alongside these experiences, a lack of awareness of what psychology service is available in the hospital was also identified. Many patients told us that they were not aware that clinical psychologists were in the hospital as they only had contact with nurses and their consultants, and they had received no information about clinical psychology in the hospital. When discussing the prospect of accessing psychology, all of these patients who had previously been unaware expressed an interest in this form of treatment, believing it could

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be helpful. This suggests that there is a breakdown in communication between the clinical psychology team and patients on the ward. Again, this issue seemed particularly prevalent on the Acute wards of the hospital wherein it does not appear to be standard practice for patients to be proactively offered psychological therapy. Rather, patients have to request access for themselves, but are not consistently informed that they are able to request this access. This relates to the theme on *Information Access* and demonstrates that many patients in the hospital are unaware of the treatments and services available, which hinders their ability to make informed decision on their care and treatment. For patients to meaningfully participate in the development of their care plan and ongoing decision-making, they need a full awareness of all their potential options. To facilitate informed decision-making regarding psychological input, full information on the clinical psychology service in the hospital should be made available to patients at the earliest opportunity.
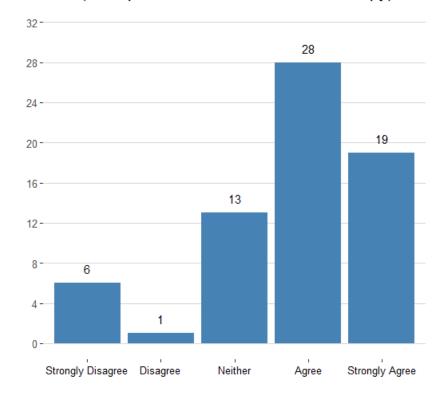
Positively, when we spoke to patients who did have access to the clinical psychology service in the hospital, they were all highly positive about the treatment they had received. Patients reported that they had found the psychological input very helpful in their recovery process, saying: "it helps you get to the route of the problem", "Talking therapy is really good", and "my psychologist is excellent". Several people additionally reported that psychological offered unique benefits to their recovery and wellbeing which a purely medical model of treatment did not afford: "It helps you to understand yourself", "psychiatry can't help everyone, psychology is important" and "I find psychology more helpful than medication". These comments demonstrate that the availability of psychological therapies is essential for patients to be able to access the highest standard of care. Lack of such access may impede recovery as patients are denied treatment which they value, and which works for them. Further, there is a significant mandate from patients to increase the level of psychological input available on the wards, as many patients are frustrated by a lack of access to psychologists and psychological therapies.

Arts Therapies

Many patients throughout the hospital are highly creative, and not only take great pleasure in artwork and music, but also find it to be a deeply therapeutic process which benefits their wellbeing and recovery. *Arts Therapies* is a theme capturing the patient experience of art and music therapy in the hospital, occupational therapy, the availability of these services, and the value ascribed to these options by patients.

One question in the survey addressed the question of whether patients felt they had enough access to therapeutic activities, including arts therapies. Patients were overall very positive about access to therapeutic activities, with 47 patients (of 67 respondents) agreeing that they did have enough access, and only 7 disagreeing.

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I Have as Much Access to Other Therapeutic Activities as I Would Like (Examples Include Art and Music Therapy)
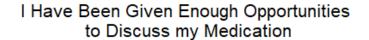

When speaking about arts and music therapy in the survey comments and group discussions patients were overwhelmingly positive. Among many other positive comments, patients said: "Art therapy is helpful – it's relaxing and people are nice, lets you vent your inner emotions", "Arts therapy is all I ever do, it's very helpful", "Doing creative work on the ward is very helpful", and "Music therapy really helps". The Artlink programme was also singled out for praise by multiple patients. Many patients stated that they enjoyed the group nature of these activities, but others also stated that one-on-one art therapy was highly valued. Access to Occupational Therapy was also noted as something that helps patients both recover and function well on the ward.

While the survey indicates that the majority of patients feel they have sufficient access to therapeutic activities, a number of patients also stated that they would like the art and music groups to run more often. For some patients, arts therapies were more helpful than anything else for their health and wellbeing, and so there was a strong desire for as much access as possible. As arts therapies are so highly valued by so many patients in the hospital it should be a priority for these services to be maintained and expanded.

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Medication

Medication was frequently identified by patients as among the most important aspects of treatment in the hospital, potentially having both positive and negative effects. *Medication* is a theme capturing the patient experience of medication, including whether patients feel there is enough discussion about their medication, patient concerns about side-effects of medication, and experiences of patients being coerced into taking medication.

There was one question in the survey specifically addressing medication which asked whether patients had been given enough opportunities to discuss their medication. The majority of patients (N=41/68) answered that they did feel they had been given enough opportunities, while 19 patients stated they had not.

I Have Been Given Enough Opportunities to Discuss my Medication

The comments made by patients in group discussions and on the surveys did not reflect this positive balance, with the majority of comments being negative. Patients identified two major problems they had experienced regarding medication.

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First, patients generally felt that they did not have enough information on the medication they were prescribed, and not enough time was spent with their doctor discussing their medication. The primary point of concern for patients on this point was information regarding the side-effects of medication, with several patients stating they had little to no information about this: "I didn't know the side-effects of my medication until another patient told me – doctors tell me nothing", "less than 5 minutes was spent talking about it, it's not good enough", "nothing [information] is offered". This lack of information is experienced as distressing, with one patient stating: "the medication I'm on scares me". Patients further expressed a desire for more support dealing with the physical side-effects of medication, stating "the physical side-effects are what's most difficult" and "the medication I'm on is crippling me".

The second major problem identified by patients regarding medication was coercive practice. Several patients stated that they felt they had no choice in medication and were forced to take whatever was prescribed to them: "I felt bullied into taking medication", "Medication is forced on me", "My medication is changed without my consent or taking my views into account". Patients spoke very strongly against these practices experiencing them as a violation of their rights.

While the majority of comments made regarding medication were negative, it is important to note that the majority of survey respondents had positive experience of medication, and several patients also recounted experiences of good practice. Several patients stated they had been involved in decisions about the medication they receive, felt well-informed about side-effects, and that their opinions and concerns had been taken into account. Multiple patients specifically stated that they had requested and received written information concerning the side-effects of their medication, and that they found this very reassuring. This links back to previous themes of *Access to Information* and *Patient Involvement*, where patients discussed that involvement and information access was possible but required persistence. It may be the case that patients who don't feel they have enough information about their medication have found it challenging to request this information. As suggested in the *Access to Information* theme, information on medication and side-effects should proactively be made available to patients upon the medication being prescribed. If patients are required to request this information themselves, there will always be a number of patients who find it challenging to do so and will subsequently be uninformed.

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Human Rights and Treatment Options

As previous stated, articles 12 and 25 of the CRPD states that people have the right to the highest available standard of health, and treatment people receive should be in line with their own will and preferences. This means that patients have the right to access a wide range of treatment options to ensure that they are getting the best treatment possible, and that this treatment is fully in line with their own preferences. As many patients expressed that they found significant value in psychological therapies and arts therapies, the provision of these treatments is necessary to ensure that patients can exercise their rights to treatment in line with their own will and preferences. Article 26 of the CRPD states that people should have access to comprehensive habitation and rehabilitation programmes which enable people to attain independence, full social, mental, physical, and vocational ability, and full inclusion and participation in life. It is further stated that these programmes must begin at the earliest possible stage and be based on a multidisciplinary assessment of the individual person's strengths and needs. Accordingly, the care and treatment patients receive should be exhaustive of all desired options, including psychological therapies and arts therapies, rather than limited to a single modality.

Under Article 9 of the CRPD, all patients must also be given access to clear and full information on the availability of all treatments and services within the hospital to ensure they can exercise their will and preferences. This should include all details of a patient's medication, including information regarding side-effects, as such information is necessary to ensure informed consent under Article 25 of the CRPD. Additionally, any practice of coercive treatment or treatment without consent of patients, including prescribing of medication, is in violation of Article 25 of the CRPD.

The Patient Rights Act (2010) states that any healthcare is to be patient-focussed, take into account the patient's needs, and provide the optimum benefit for their health and wellbeing. Patients clearly state they find value in accessing a range of treatment options, and that treatment being limited to only medication has an adverse effect on their wellbeing. Accordingly, provision of multiple forms of treatment is a necessity to be in line with the Patient Rights Act (2010). Core principles of the Mental Health Act (2003) also state that services must look at a full range of options for patient care, take the wishes of patients into account, and provide the maximum benefit. Additionally, a core principle of the Mental Health Act (2003) is that no patient or group of patients should be treated less favourably than other patients. The disparity in access to clinical psychology for older patients is in violation of this principle.

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Theme 3: The Social Patient

The relationships patients have both with staff and other patients are vitally important in determining the quality of their experience in hospital. Positive social interactions and social support are greatly valued by patients, while negative social dynamics or loneliness can severely exacerbate a patient's suffering. *The Social Patient* is an overarching theme comprised of three themes which capture the social experience of patients in the hospital. This theme covers the quality of relationships patients develop in hospital, the impact these relationships have on their overall experience, the experience of being treated like an individual, and loneliness in the hospital. The three themes are: *Patient-Staff Interactions, Person-Centred Care,* and *Social Isolation & Loneliness*.
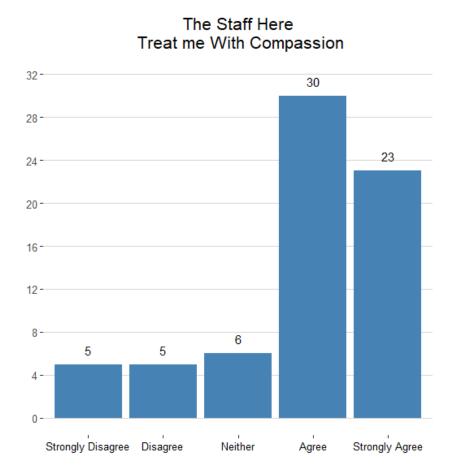
The central message underpinning all three themes is that patients are social beings, and positive social interaction is a fundamental human need. The social support and interactions offered in hospital, form both staff and other patients, can be critical in promoting recovery. Patients place an extremely high value on being treated as individuals, and are deserving of compassion, respect, and kindness. When these needs aren't met, when patients experience mistreatment or social isolation, there can be severe consequences for their wellbeing.

Patient-Staff Interactions

Patients spend a lot of time on the ward interacting with staff, and these interactions significantly influence how supported patients feel, how safe they feel, and their overall wellbeing. One question in the survey directly addressed patients' perceptions of how they are treated by staff. When asked if staff treated them with compassion, the overwhelming majority of patients (N = 53/69) responded positively, with 10 patients responding negatively.

This positive balance is also reflected in the additional comments from the surveys and group discussion, which provide further insight into patient perceptions of staff and patient-staff relationships. Relationships with staff and staff-patient interactions were very common points of discussion across the feedback events, and the vast majority of comments patients made about staff were highly positive. A great number of patients spoke of staff in glowing terms, describing them as "Brilliant", "Wonderful", and "Amazing". Patients praised staff for their kindness, respect, compassion, and empathy. Nurses on the ward were regularly singled out, with patients saying: "Nurses are always trying their best to help", "The nurses are all very helpful", and "Nurses work very hard". The support offered by the ward staff was particularly valued by patients and seems to be an essential component of recovery. Some of the most important qualities in staff identified by patients which helped to develop a supportive, therapeutic environment were: "staff are genuinely interested in you", "[staff]

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always want to help", and "[staff] believe in my ability to get better". One long-term patient specifically noted that staff attitudes toward patients have "improved a lot over time". Multiple patients also expressed sympathy for the nursing staff, stating that they thought nurses were "undervalued", "overworked", and deserving of increased pay.
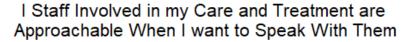
The Staff Here
Treat me With Compassion

While the majority of patients spoke positively about staff, a small number of patients spoke of more negative experiences. The majority of these comments related to patients not feeling respected by staff, with patients saying: "Staff don't take your feelings into account" and "I don't feel respected as a human being". Patients additionally spoke of how some staff don't understand patients, and of feeling "bullied", "antagonised" and "threatened" by staff. Some patients further stated that they had suffered major distress due to staff triggering their PTSD symptoms or not taken their history of trauma seriously. This speaks to the necessity for all staff to be trained in a trauma-informed approach to care and treatment as a history of trauma is highly common in people experiencing mental health problems.

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Person-Centred Care & Treatment

Alongside the attitudes and behaviour of individual staff members, the facilitation of person-centred care and treatment is a hugely important factor effecting the patient experience. Being treated as an individual with unique strengths, experiences, and needs demonstrates to patients that they are valued as human beings, and this has significant benefits for their wellbeing. *Person-Centred Care* is a theme which captures the patient experience of being treated as unique individual, the amount of one-on-one time patients have with staff, and the value patients ascribe to this model of care.

One question in the survey indirectly addressed this topic, asking patients whether they felt the staff involved in their care and treatment were approachable when they wanted to speak to them. The overwhelming majority of patients (N = 48/69) answered positively, with 12 patients answering negatively. This would suggest that most patients feel that the staff on wards take the time to speak with them as individuals and are attentive to their needs.

I Staff Involved in my Care and Treatment are Approachable When I want to Speak With Them

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Despite the positive response to the survey question, several patients expressed the view that the hospital does not treat them as individuals, but rather adopts a "one-size fits all approach". Patients said that the "hospital only sees you as a patient, not a unique person with different needs and strengths" and that "people aren't given space to recover at their own pace". Patients spoke of not getting enough consistent one-on-one time with staff and a lack of meaningful discussion about why they are experiencing symptoms and feel the way that they do. This connects to the theme of *Clinical Psychology*, and particularly the lack of access to psychological input that many patients report. Psychological therapies offer a space for patients to engage in this meaning-making process and the development of a better understanding of oneself. The provision of psychological therapy to interested patients is an essential component of person-centred care in this regard, providing patients with individualized care tailored to their unique needs. Conversely the lack of access to psychological input may leave patients struggling to make sense of their mental health needs and contributes to the experience of patients feeling that the hospital does not see and treat them as individuals.

When patients did experience individualised care and one-one-one time with staff who took the time to understand them, this was "greatly appreciated" and described as "extremely important" and something which "helps a lot". Patients identified that your keyworker is critical in you receive this kind of individualised care and treatment and spoke very highly of their keyworkers. However, several patients were not even aware of who their keyworker was.

A number of patients specifically spoke of the amount of time they spent one-on-one with their consultant, identifying this as an important component of person-centred care. Several comments were made regarding the amount of time patients spent with their consultant, with patients reported largely mixed experiences. Regardless of their positive or negative feelings, patients clearly identified contact with consultants as valuable, with consultants being framed as an important source of information and being able to facilitate or prevent patient involvement.

On the negative side, patients spoke of very rarely seeing their consultant and desiring more time, stating "If I saw my doctor more often I wouldn't have needed to stay as long as I have", "There's a lot of difficulty in accessing doctors", and "I would like to speak to doctors more about medication". For these patients, the lack of time spent with their consultant was a barrier to recovery and accessing quality treatment. Positively, patients also described

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being able to develop a good relationship with their doctor which they were thankful for and helped in their recovery: "My consultant meets with me weekly and we work together on changes to my care", "I get on well with my doctor – we discuss things together and I'm supported to make decisions". For these patients, their consultants facilitated a collaborative approach to their care and treatment promoting patient involvement and autonomy, and this was highly valued. These examples demonstrate the diversity of experience of patients in the hospital, and the important role played by consultants.

A critical aspect of person-centred care discussed by patients is the impact of a patient's diagnosis and first impression. Patients spoke of being judged based on their initial diagnosis and the label they've been assigned, rather than being seen as a whole person, stating "The first impression doctors and the system have of you is very difficult to get rid of" and "Doctors still see me and judge me by my initial state". This is experienced as dehumanising and causing feelings of hopelessness for patients. Some patients felt that no matter how hard they work or how much time passes, they are still seen as who they were at their lowest point. One patient shared that they had been "labelled" in this way more than 20 years ago, and this label has never gone away. Patients additionally described the impact of a contested diagnosis as "making things more difficult for me" and as something that can seriously inhibit recovery: "Having the wrong diagnosis is very frustrating and stops you from getting well". Rather than a focus on diagnoses and deficits with persistent negative judgements, patients stressed the importance of recognising the strengths and hard work of patients and acknowledging how much someone has changed. This connects to the theme of *Patient Involvement*, and the importance of centring the patient voice in their own care and treatment. When patients are shut out of discussions and decisions about themselves, they are increasingly seen as less of a whole person, and more as a problem to be solved. This contributes to a poor quality of care, as the unique insights patients can offer about their own recovery and wellbeing are ignored or dismissed.

Staffing levels on the ward can have a serious impact on the provision of person-centred care. Several patients shared their experience of the ward appearing to be understaffed. Patients expressed concern for staff when discussing staffing levels, saying that they felt staff often seemed "overworked" and "extremely busy", and that nurses on the ward "deserve more support". Many patients praised staff despite this, emphasising that even when busy staff always make an effort to talk to patients and be available and approachable. However other patients experienced the impact of understaffed wards, saying they often felt "ignored" and that it could be difficult to valued have one-on-one time

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with staff. A reliance on bankstaff was also seen as problematic, as some patients feel that this can cause communication to "break down", and the bankstaff's lack of knowledge of individual care-plans can cause patients to feel "unsafe".

Loneliness

Patients are social beings, and so the experience of loneliness and isolation can have a severe negative effect on patient wellbeing, and act as a major barrier to recovery. The previous patient experience work identified that many patients cite loneliness as a central aspect of their experience in the hospital, and this finding was replicated in the current project. *Loneliness* is a theme capturing experiences of loneliness and isolation in the hospital, factors contributing to loneliness, and the benefits patients ascribe to the friendships they make in hospital.

To explore the prevalence and experience of loneliness, one question in the survey directly addressed whether patients felt lonely in the hospital. The results were evenly balanced between patients who reported feeling lonely (N = 29/69) and those who said they didn't feel lonely (N = 29/69).

I Feel Lonely or Socially Isolated in the Hospital

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The qualitative comments made in the surveys and group discussions demonstrates that friendships with other patients are highly valued. Friendships with other patients improves the ward atmosphere and makes patients feel more comfortable living on the ward: "It's a friendly ward; patients get on well and make their own activities", "You can have friendly relationships with other patients on this ward which helps being here". Multiple patients identified being able to build relationships with both patients and staff as the most valuable aspect of their time in hospital. Patients also discussed the value in meeting people with similar experiences to their own, and how supportive and understanding relationships can help with recovery: "Meeting people like myself is particularly good", "Been able to make friends on the ward with other patients – these positive relationships help with recovery". The coffee and newspaper mornings hosted by rec nurses on some of the wards were specifically highlighted as providing good opportunities for both patients and staff to socialise together.

While many patients discussed the benefits they had received from developing friendships with other patients, they also expressed a desire for the hospital to have a stronger emphasis on socialising. Simply having conversations, particularly in groups, was expressed to be very helpful to patients at combatting loneliness and boredom: "Group conversations like this [referring to the feedback event] are really good, better than everyone just sitting on their own", "There needs to be more talking with people".

For the patients who did report feeling lonely or socially isolated, a number of factors contributed to this. For many patients, separation from family and friends was the main driver of loneliness. A lack of passes compounded this, leaving people feeling cut off from their community and life outside the hospital: "I feel lonely due to restrictions on passes to visit my family and friends", "I haven't been able to maintain connections with my family which I find very distressing". Other patients spoke of the difficulty in first arriving on the ward, and the feeling of being surrounded by strangers. While many of these patients would go on to make friends on the ward, their early experiences were very difficult and caused them to feel very isolated. This suggests that a patient's introduction and first days on the ward are a particularly vulnerable time for feelings of loneliness, and patients may benefit from more social engagement during this time. Patients also reported instances of being left to sit alone in their room or communal areas for hours without anyone to talk to, leaving them feeling very isolated and lonely. These patients suggested that staff should be more proactive in interacting with patients and offering them opportunities to socialise.

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Human Rights and The Social Patient

The right for patients to be treated with respect, compassion, and dignity by all staff is protected by Article 25 of the CRPD, which recognises the rights of patients to the highest attainable standard of health care. Further to this, Article 3 states that acceptance and respect for the inherent dignity of persons are general principles underpinning the CRPD. The right to person-centred care is protected by Article 26, which states that services and programmes should be based on a multidisciplinary assessment of the unique needs and strengths of the individual. Article 26 further specifically states that programmes and services should enable persons to attain and maintain full social ability. Accordingly, problems of loneliness and social isolation must be addressed.

The Patient Rights Act (2011) states that all people have the right to be treated with consideration, dignity, and respect when using any NHS services. This includes compassionate and respectful treatment by all staff working in the hospital. A core principle of the Mental Health Act (2003) states that treatment should be provided which gives the maximum benefit. Given the significant impact interactions with staff can have in patient wellbeing, being treated with respect and compassion at all times is necessary for patients to receive care of such a standard.

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Theme 4: The Patient Journey

Much of the preceding discussion makes it clear what patients want from the hospital: a safe, supportive, and therapeutic environment in which they receive the help they need. Positively, most patients do find the hospital to be a helpful place which supports their recovery. However, patients also want to spend as little time in hospital as necessary and reach a point in their recovery wherein they can return to living in the community. Patients emphasize that a clear pathway to discharge and continuity of care between hospital and community is essential to avoid becoming 'stuck' in hospital, and to maintain recovery and wellbeing after leaving. *The Patient Journey* is an overarching theme encompassing the overall experience and journey of patients in the hospital. It is comprised of three themes which capture what is helpful and unhelpful about being in hospital, the factors which make patients feel safe or unsafe, and the patient experience of the pathway to discharge. The three themes are: *Recovery, Safety,* and *Leaving Hospital.*

The central message underpinning all three themes is that, for the majority of patients, the hospital does function well as a safe and supportive environment which helps people to recover. Many patients value the treatment they receive here and feel that the hospital has enabled them to make significant progress in their recovery. However, as illustrated elsewhere in this report, there are several factors working against patients which can make them feel unsafe and undermine their recovery, adversely affecting their experience of being in hospital.
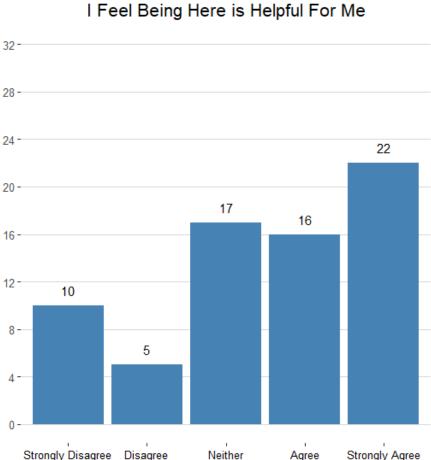
Recovery

A patient's time in hospital is a complex period with multiple factors both internal and external to the hospital contributing to whether this time is experienced as helpful or unhelpful. Most patients ultimately experience the hospital as a very helpful place which supports their recovery and wellbeing, however this is not the case for all patients. The theme of *Recovery* captures what patients find valuable about being in hospital, what factors contribute toward their recovery, and the factors hindering recovery.

One question in the survey asked patients about their overall experience of being in hospital, specifically whether they felt being in hospital had been helpful to them. The majority of patients (N = 38/70) stated that being in hospital had been helpful for them, while only a minority (N = 15/70) said that it had been unhelpful.

Additional comments made on the survey and the group discussions held with patients provide insight into what it is patients find helpful or unhelpful about being in hospital. The

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role of the hospital in facilitating patient recovery was a frequent topic of discussion. The overwhelming majority of comments spoke positively about the hospital's role in supporting patient recovery.

I Feel Being Here is Helpful For Me

Many patients felt they had made significant progress in their recovery through their time in hospital, emphasizing a huge contrast between how they felt upon admission to how they felt in the present: "Hugely helpful being here, I've retained my natural personality", "Being on the ward has lifted my depression", "I've improved a huge amount over the past few months", "I've come leaps and bounds since I came here". These comments demonstrate that a large number of patients have an overall positive view of their time in hospital and regard their time being here as significantly helping their recovery: "Eden is sheer perfection; couldn't have been better"; "I'm so happy I ended up on Balcarres".

Numerous positive effects of being in hospital were described. Learning about oneself and becoming independent were the most frequently cited benefits of being in hospital: "Being here has helped me understand my illness", "I can put what I've learned in my recovery into practice", "I've learned more about myself".

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Education, learning more about oneself and developing resilience and coping skills, was viewed as a collaborative process between patients and staff which helps to facilitate patient independence: "The ward is good at encouraging patients to build independence", "I feel supported by staff in getting ready to leave", "I have the strength to keep getting better and do well on my own". This links back to the theme on *Patient Involvement* and demonstrates that patients consider working collaboratively and building autonomy to be essential components of recovery.

Patients also praised the hospital's role in helping with substance misuse problems and the role this plays in recovery: "Staff have been really helpful dealing with my withdrawal symptoms", "Being here has helped me stop drinking which has helped me".
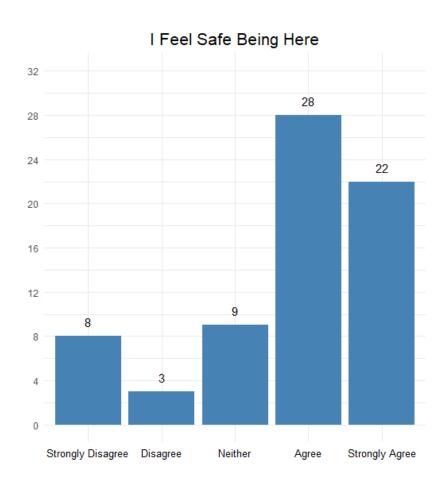
A small number negative comments were made regarding the hospital's role in recovery which illuminate why some people stated they do not find being in hospital to be helpful. Several patients stated that the hospital wasn't helpful because they didn't need to be in hospital in the first place: "I do not believe I have an illness that requires hospitalisation", "There's nothing wrong with me, medication makes me worse and I'm forced to take meds". For some the hospital was seen as doing more harm than good: "I've crawled 2 steps forward and they've dragged me 20 steps back". Other patients expressed that being in hospital felt more like a punishment rather than something for their own benefit: "Being here is a violation of my human rights – I don't need to be here", "Being here feels like a punishment".

A number of patients with spoke of how external factors could also hinder their recovery in hospital. Financial issues, particularly involving benefits, were seen as complications which made it difficult to get better while in hospital. These patients expressed that more assistance with these issues, perhaps through better access to social workers, would allow them to better focus on their recovery. Being separated from one's family and community was also viewed as a highly negative aspect of being in hospital.

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Safety

To feel safe and secure is a foundational human need, and so safety is an important factor in determining a patient's overall experience in the hospital. A safe and supportive environment is conducive to recovery, providing patients with a sense of security at a time when they are at their most vulnerable. Conversely an unsafe environment acts as a major barrier to recovery, as the hard work of recovery is made significantly more difficult when more basic needs are not met. The theme of *Safety* captures the importance of feeling safe in hospital, the role of staff in creating a safe environment which promotes recovery, security issues with personal property, and what factors contribute to patients feeling unsafe.

One question in the survey asked whether patients felt safe in the hospital. The vast majority of patients (N = 50/70) reported that they did feel safe, with only a small number of patients (N = 11/70) saying they did not feel safe. Safety was highlighted as a very important aspect of the patient experience, with one patient stating: "You can't be hopeful without being safe; feeling safe is the most important thing".

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In the qualitative comments in surveys and in group discussions, patients reported mixed experiences on feelings of safety in the hospital. Regarding the positive comments, patients praised the efforts of staff in creating a supportive environment which helped people to feel safe: "It's a supportive environment and a safe place to be", "There are always staff around to ensure our safety. It was also expressed that other patients as well as staff contribute positively to this environment: "I do feel safe here, staff and patients keep me safe, we all keep each other safe". This links back to the theme of *Loneliness and Friendships*, demonstrating how a strong sense of community on a ward helps patients to feel safe and secure.

A major issue contributing to patients feeling unsafe on the ward was the occurrence of property theft. Personal property being stolen was described as being very distressing and upsetting to patients, and the lack of investigation into these incidents as very unsatisfying. Experience of theft results in patients feeling vulnerable on the ward as the ward no longer feels like a safe or secure place, but instead somewhere they might be victimised. Patients noted that there is lack of good security or alternative storage which leaves them with few options regarding their private property. Alongside issues of theft and personal belongings, patients also described the experience of having their room searched by staff as being highly distressing. Many patients, particularly long-term patients, view the hospital and their room as being their home, and so having staff invade their personal space in such a manner is experienced as a violation. If patients do not feel that they have their own private safe space in their room, they feel more vulnerable living in hospital. One patient described the experience of watching staff search their room as: "Really traumatic, I was just watching them go through everything feeling worse and worse, it didn't need to happen".

While many patients develop friendly relationships and experience a feeling of camaraderie on the ward, conflict with other patients can be a reason for feeling unsafe. Patients described incidents of other patients being abusive or violent towards them, with one patient stating this is a frequent occurrence that hasn't been adequately addressed. Staff could also play a role in making patients feel unsafe, with the power dynamic between staff and patient making patients feel vulnerable to potential abuse. The threat of sedation and antagonising behaviour from staff were specific examples of this raised by patients. Some patients expressed that there isn't enough oversight and supervision in the hospital and this was felt to contribute to the feeling of patient vulnerability. It was suggested that there should be more recourse for patients to raise issues they've experienced with staff when they feel they are being mistreated.

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Arriving onto the ward is a particularly vulnerable time for patients which can heavily determine whether they feel safe or unsafe in a new environment. One patient described their initial arrival as being highly distressing, as several things on the ward were experienced as triggering. This patient suggested that more preparation and discussion before coming onto the ward itself could have eased the transition and helped them feel safer. Numerous patients described the experience of being escorted into hospital by police as being distressing, making patients feel less safe and increasing the difficulty of transitioning to the hospital: "It's very distressing to arrive on the ward in handcuffs escorted by the police". Patients feel that police shouldn't be involved in bringing people to hospital as it creates a negative first impression, making the hospital feel more like a punishment or prison rather than a place to help you recover: "Police aren't the appropriate people to bring someone to hospital – it makes you feel like a criminal".

Leaving Hospital

Preparing to leave the hospital is one of the most critical points in a patient's journey and recovery. It is a time when patients are highly vulnerable as they leave the highly supportive environment of the hospital, and transition into the potentially less supportive community. *Leaving Hospital* is a theme concerning this point in time. It captures the patient experience of the discharge process, their primary concerns about what happens after they leave hospital, accommodation issues, transitioning into the community, and the effects of spending too much time in hospital.

Across acute and rehab wards patients discussed the idea that a longer length of stay in hospital can potentially have detrimental effects on recovery, even if an initial hospital stay may have been helpful: "I've been here too long – it was helpful at first but now it's making me worse and undoing progress", "I've been here longer than I needed to be", "If you're here for too long it has a negative effect". Patients identified that there was an 'ideal' length of time for one to spend in hospital, and that being discharged too late can be just as damaging as being discharged too early.

A major factor in problems related to one's length of stay in hospital is the discharge process. Patients predominantly described a negative experience of the discharge process, with almost every comment relating to the discharge process being negative. One issue

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experienced by many patients was a lack of collaborative work during the discharge process – patients felt uninvolved in planning their own discharge and were unclear of the steps they needed to take to move this process along: "There needs to be more discussion with patients approaching discharge", "Patients don't have much say in the discharge process".

This lack of involvement can create anxiety and uncertainty in patients, as it means people don't know what's going to happen to them. It additionally disempowers patients, as they are prevented from making plans for the future and taking ownership over their own recovery, and instead have the stages of their recovery dictated to them. Particularly in Acute wards there is a perception that discharge can be a very sudden and abrupt experience which leaves patients unprepared and vulnerable to negative outcomes: "There needs to be more discussion with patients approaching discharge", "There isn't enough emotional preparation during discharge".

In Rehab wards, patients commonly struggled with not knowing what they had to do to start moving towards discharge and leaving hospital: "There's no clarity or information about getting discharged, I don't know what I need to do to leave". Many patients we spoke to felt during their time in hospital they were stuck in a holding pattern, without clearly identified goals and plans for making progress towards their recovery. This was described as a frustrating experience, as patients felt that it resulted in a significant amount of time passing without meaningful progress – with some patients stating that years had gone by without things changing for them.

The issues patients have with the discharge process strongly ties into the themes of *Patient Involvement* and *Access to Information.* When patients aren't involved in their own care and aren't kept fully informed with what is happening, their wellbeing inevitably suffers. To avoid setbacks in recovery, it is necessary for patients to be involved and informed throughout all stages of their hospital journey, including during discharge.

It was additionally expressed across all wards of the hospital that there is little continuity of care between hospital and community, resulting in a discharge process which feels unsupportive: "There's no smooth transition between hospital and community, you have to struggle".

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Despite the majority of patients reporting negative experiences, a small number of patients highly praised the discharge process, describing it as an involved and collaborative process which left them feeling supported and prepared to leave. This suggests that for some patients the discharge process works well, and there may be a lack of consistency in the discharge planning process.

For many patients, the primary concern around discharge was their accommodation. Patients with previous experience of being discharged and later readmitted to the hospital explained that being discharged into poor accommodation disrupts recovery and the progress a patient achieved while in hospital: "Poor accommodations after discharge can undo all the work you've done in hospital to recover". Multiple patients described being discharged into an unsafe environment, identifying this as a traumatic experience which directly led to their need to be readmitted: "The discharge process can feel like you are being lied to and set up to fail, I feel betrayed". Patients expressed a desire for more involvement in deciding where they are discharged to when leaving hospital, arguing that if patient views were taken into account the damaging experiences described above could be avoided and readmission rates would be reduced.

Human Rights and The Patient Journey

Issues raised under this theme are primarily covered by Article 25 of the CRPD, which states that persons have the right to the highest attainable standard of health care. As leaving hospital is a particularly vulnerable time for patients, it is necessary for patients to have a comprehensive discharge plan to ensure they continue to receive the highest attainable standard of care. Good continuity of care between hospital and community services is essential to maintain a high standard of care and protect patient wellbeing. Under Article 3 and the general principles of the CRPD, patients should be fully involved and supported in developing their discharge plans, and their plans should reflect their own will and preferences. Under Article 26 of the CRPD, any discharge plans should be prepared with multidisciplinary input, and support physical, mental, and social recovery. Under Article 26 discharge plans should further consider how to support patients to engage with employability services, volunteering opportunities, education, and further training. Article 19 states that disabled persons have the right to choose their place of residence and are not obligated to live in particular living arrangements, and further to this should have access to a range of in-home and community support services. Accordingly, any discharge planning should ensure that patients are involved in choosing their future accommodation and continue to receive support after leaving hospital.

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Relevant to Article 25, a number of patients identified that after a certain time, being in hospital was no longer helpful to them and they would be better served in the community. These patients expressed that being in hospital could in fact adversely affect their recover. Under these circumstances, a too long length of stay in hospital could be argued as violating a person's right to attain the highest standard of care. Relevant to patients who state they should never have been in hospital, Articles 12 and 14 of the CRPD protect against the practice of coercive treatment, treatment without consent of patients, and involuntary detainment.

Article 22 of the CRPD states that no person, regardless of their living arrangements, should be subjected to arbitrary interference with their privacy or home. Patients exercise the right to privacy in their own room, and for many patients the hospital ward and their room is effectively their home, particularly patients who have been in hospital for several years. The searching of a patient's room without their permission, and without good cause, may then be in violation of the CRPD. Article 28 of the CRPD states that persons have the right to social protection, and this should be ensured through access to social protection programmes, poverty reduction programmes, and financial assistance from the state. Accordingly, patients struggling with finances and issues accessing benefits should be supported by the hospital to access the programmes and resources which can enable them to solve these issues.

The right to a comprehensive discharge plan, and the right for patients to fully participate in preparing their own discharge plan, is additionally protected by the Patient Rights Act (2010) and the Mental Health Act (2003). Core principles of both acts are for care and treatment to be patient-focussed, to support the patient to be involved in decision-making as much possible, and for patients to be provided with all relevant information in order for the patient to participate. Both acts further state that care must provide the optimal and maximum benefit to the patient. As a lack of patient involvement in discharge is shown to adversely affect patient wellbeing, this further necessitates patient involvement.

Theme 5: Life on the Ward

While patients spend a lot of time in hospital trying to get better, the ward also acts as a temporary home for patients where they may spend a significant amount of time. *Life on the Ward* is an overarching theme capturing the patient experience of day-to-day life on the ward, concerning issues of how patients spend their time, the physical ward environment, the hospital facilities, and the food available in hospital. This theme is divided into two themes: *Boredom & Activities* and *Facilities & Ward Environment*.

Boredom & Activities

Boredom and a lack of things to do on the ward is a frequent issue brought up in the Patients Council's group advocacy meetings, with patients often stating that boredom has a significant negative impact on their wellbeing. *Boredom & Activities* is a theme concerning how patients spend their time on the ward, the negative effects of boredom, the importance of activities, and appreciation patients have for rec nurses. One question in the survey directly addressed the question of whether patients feel bored living in the hospital. The majority of patients stated that they do feel bored on the ward (N = 39/67), while a number of patients (N = 16/67) stated they did not feel bored.

I Feel Bored on the Ward

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In the qualitative comments from surveys and group discussions, patients reported largely mixed experiences regarding levels of boredom and activity on the ward. The effects of boredom were described as being very serious, with patients saying: "The boredom is mind-rotting and ineffective as therapy" and "Boredom on the ward makes me incredibly depressed". A lack of passes was cited by many patients as contributing to boredom on the ward. A number of patients noted that when activities were available, they were often things that weren't of interest to them, suggesting that patients should have more involvement in designing activity programmes on the ward.

Rec nurses and activity nurses across multiple wards were frequently singled out for praise by patients who appreciated the effort put into arranging activities. Activities which afforded patients chances to socialise, such as the coffee mornings held on some wards and group activities, are well-liked. More physically active and engaging activities like going on trips outside the ward, nature-walks, and going to the gym were also praised. Volunteering work was also highly valued by patients specifically for helping people to feel "productive". More access to volunteering opportunities was noted as something that could help people with their recovery. Alongside volunteering, access to nature and gardening activities were also noted by patients as activities that can actively help in recovery. Activities which allow patients to express themselves creatively, such as artwork and playing music, are also highly valued by patients.

Facilities & Ward Environment

The physical ward environment and facilities available to patients undoubtedly influence the patient experience. *Facilities & Ward Environment* is a theme capturing patient views on the physical environment of the ward, the facilities in the hospital such as the Hive and the library, and the food available in the hospital. Patients reported largely mixed views on the facilities in the hospital and ward environment, describing both positive and negative aspects. A large number of the negative comments referred to the temperature of the ward, with several patients complaining that the ward gets very cold, describing it as "freezing". Staff on the ward echoed many of these complaints additionally. Complaints about the temperature were exclusive to the acute wards on the hospital, with patients on the Rehab wards and Older Peoples not experiencing this problem. Additional complaints regarding the ward environment included the high level of noise on the ward, particularly the sound of buzzers and doors banging, the bright lights, and uncomfortable mattresses. Multiple patients additionally stated that the colour of paint in their rooms was too strong, and they would prefer something more calming.

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The hospital facilities were praised as "excellent" by patients, and it was noted that the new building of the hospital is very clean and well-built. Having your own private room was something very highly valued by patients, particularly those who had previous experience of having to share a room while being in hospital. Private rooms were praised for making communal spaces "less disruptive" and also "giving you somewhere to go when you're feeling bad". The Veranda Café, the Hive, and the hospital library were also identified as being important to patients for providing additional recreation and social opportunities. The library was particularly praised by patients in rehab wards for offering educational resources which help facilitate rehabilitation and provide opportunities to develop skills which can help patients transition into further education or work.

Garden access was praised on all wards which contained their own garden for patients to use. Being able to access green space was considered important by patients as a refreshing change from the indoor environment of the ward, and patients reported enjoying being able to participate actively in cultivating the ward garden. Garden access was also praised as beneficial for providing additional places for patients to interact socially with a degree of privacy.

One patient suggested that they would like to see a hospital recycling programme that patients could participate in. The patient was concerned about the amount of waste produced by the hospital and felt that a recycling programme would not only benefit the environment, but would also provide an engaging, practical activity for patients.

Several comments were made regarding the quality of food in the hospital, with the majority of comments being positive. Patients praised the variety of options and availability of healthy food and said that the quality of food had noticeably improved over recent months. Negative comments primarily focused on the variety of food available, with patients expressing a desire for more options and choice, as well as problems with menus resulting in patients not getting what they selected.

Human Rights and Life on the Ward

Article 25 of the CRPD, which affords patients the right to the highest available standard of health and treatment, is relevant to issues of boredom in the hospital. Patients discussed that boredom could have severe adverse effects on their wellbeing and recovery, and so

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boredom acts as a barrier to patients attaining the highest standard of health and treatment. Article 30 protects the right of patients to participate in cultural life, recreation, and leisure. This includes ensuring access to services such as theatres, museums, and cinemas, and so encourages activities taking place outside the ward. Article 30 additionally states that patients should be enabled to develop and utilize their creative, artistic, and intellectual potential. This means that patients should have full access to creative and artistic activities such as artwork and musical instruments, and the ward should be an engaging and stimulating environment. Complaints related to the facilities and physical environment of the ward relate to Article 28 of the CRPD. Article 28 protects the rights of patients to an adequate standard of living conditions, including food, and for these living conditions to be continuously improved.

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Key Messages & Recommendations

The results of the Patient Experience project provide a rich and nuanced account of what it is like to be a patient in the Royal Edinburgh Hospital. Patients have generously shared their experiences, the difficulties they face in hospital, what they find to be most helpful, and their suggestions for how the hospital can better support patients. The Patients Council has developed the following key messages and recommendations from the experiences people have shared throughout the project. All of the recommendations made have the backing of a strong patient mandate and are in line with a human-rights based approach to care and treatment. Further to this, the Patients Council emphasizes the critical importance of involving patients in any endeavour to improve the experience of patients in the hospital. As demonstrated in this report, patients are uniquely positioned to provide insight and nuance on what life is like in hospital, and the centring of the patient voice is essential to promote the best possible practice.

A Rights-Based Approach to Mental Health

A human rights-based approach to mental health is one which prioritizes the rights, will, and preferences of patients. This approach respects the autonomy and independence of patients, empowering patients to take an active, authoritative role in their own care and treatment, rather than being passive recipients of care. This represents a movement away from 'substituted decision-making', in which decisions are imposed upon patients, and towards 'supported decision-making', in which patients themselves are supported to be the decision-maker. Throughout the Patient Experience project patients expressed a strong preference for this approach to care and treatment, citing the value of having their voices heard. Patient empowerment was identified by patients as hugely important in shaping their experience in hospital, with patients feeling that being involved in their own care significantly benefits their recovery. Conversely not being involved in your own care and treatment, and being uninformed about what's happening to you, was reported by patients to make recovery more difficult and cause significant distress and frustration.

Promisingly, many patients in the hospital do report feeling that they are supported to be involved in making decisions about their care and treatment, and that their care plan reflects their will and preferences. However, a large number of patients shared experiences of not being involved in their own care and treatment and reported that the treatment they received did not reflect their will and preferences. Alongside this, many patients shared that they were not kept adequately informed about their own care and treatment, with several patients reporting they had no knowledge of what was in their care plan. Access to information and opportunities to meaningfully engage and participate are essential components of a rights-based approach to mental health. The denial of information and

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these opportunities disempowers patients, inhibiting effective recovery and violating patient rights.

The Value of Psychology

Access to psychological therapies was routinely spoken of as one of the most important resources available in the hospital, an aspect of care critical to effective recovery. Patients expressed that psychology offered unique benefits to their recovery and wellbeing not afforded by a purely medical model of treatment, and the meaning-making process of psychology was of vital importance. However, many patients throughout the hospital, particularly in the Acute and Older Persons wards, reported a lack of access to psychological input despite it being something they believed would help them. Many patients further lacked any knowledge of the psychological services in the hospital and reported that nobody had told them it was available. To ensure that all patients are able to attain the highest standard of care and access treatment in line with their will and preferences, it is essential that the clinical psychology services in the hospital are made available to all patients.

Trauma-Informed Care

A trauma-informed approach is essential to providing the highest quality standard of care. A history of trauma is highly prevalent in people with mental health problems, and it is possible for the hospital to re-traumatise patients if the treatment they experience reminds them of previous adverse events. To provide the highest standard of care and navigate histories of trauma, it is necessary for the hospital to provide a safe, supportive, and therapeutic environment. While the majority of patients do find the hospital to be a helpful place where they are supported to get better, patients identified several aspects of being in hospital with the potential of causing trauma or re-traumatisation. Excessive restrictions, seclusion, non-consensual or coercive treatment, poor treatment from staff, and the use of restraint were issues identified by patients as having severe consequences for their wellbeing and inhibiting recovery. To provide a high standard of care it is absolutely critical for the risk of trauma and re-traumatisation to be as low as possible. To enable this, it is necessary for the hospital to deliver person-centred and collaborative care, with the least necessary level of restrictions, and promote patient independence and autonomy.

Pathway to Discharge & Transition into the Community

The majority of patients shared that their experience in the hospital was positive and that the hospital was a helpful place to be. However, many patients described encountering problems with the discharge process which threatened to undermine their recovery and the

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helpful effects of being in hospital. The major problems included patients not being involved in discharge planning, not knowing what they had to do in order to get discharged, and a lack of support during discharge. A common consequence of these problems with the discharge process was that patients felt they spent more time in hospital than necessary. Patients identified that even when they had experienced the hospital as a helpful place to be which supported their recovery, being in hospital for longer than necessary due to these issues could undo all of the progress they had made.

Patients also discussed experiencing a lack of support when leaving hospital and transitioning back to living in the community. Patients reported that there is little continuity of care between hospital and community, and that there aren't enough resources in the community to support people after they leave hospital. Appropriate accommodation was identified as a particularly prominent issue in the transition between hospital and community, with careful planning being necessary to sustain recovery. Several patients recounted experiences of being discharged into unsafe and unsuitable environments, saying that these negative experiences directly led to their being readmitted into hospital.

The Importance of Relationships

The relationships patients make with both staff and other patients are extremely important factors in determining how people feel about their experience in hospital. The majority of patients report having very positive relationships with staff. Patients praised staff for being compassionate, kind, respectful and empathetic to patients. Nurses on the ward were regularly described as hardworking and dedicated to supporting patients and patients identified this support from nurses as crucial to their recovery. However, despite this overall positive perception of staff, a common experience of patients in the hospital is feeling that you are not treated or seen as an individual. Patients shared that they often feel judged on the basis of their diagnosis rather than as a whole person, and that their unique strengths and support needs aren't properly acknowledged by the hospital.

Patients also frequently shared that they felt very lonely and socially isolated in the hospital. This is a long-standing problem, as the previous phase of the patient experience project also identified that many patients cited loneliness as a key part of their experience in the hospital. Loneliness can have a severe negative effect on wellbeing, and for some patients it can be the most difficult part of being in hospital. Conversely, other patients reported on the importance of the relationships they had made with both staff and other patients, describing these relationships as important factors in supporting their recovery. In fact, some patients stated that the friendships they had made on the ward were the most valuable and helpful part of being in hospital. This illustrates the importance of combatting loneliness in the hospital, as positive social relationships can be hugely beneficial to patient wellbeing and recovery.

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Recommendations

The hospital should embrace a human rights-based approach to care and treatment and make concrete changes in policy to move towards compliance with the United Nations Convention on the Rights of Persons with Disabilities. In line with this, the hospital should shift towards a model of 'supported decision-making' and away from the practice of 'substituted decision-making'.

The hospital should adopt a rigorous trauma-informed approach across all levels of care. This should include an evaluation of current hospital policy regarding the use of restraint, restrictions, and non-consensual treatment, and the training of all staff in trauma-informed care.

The hospital should aim to involve patients as much as possible in developing their own care plan, and in making decisions about their own care and treatment. Care and treatment should be patient-led and patients should be supported to make decisions, rather than decisions being made for them. The treatment patients receive should reflect their own will and preferences as much as possible and prioritise their human rights.

Patients should be better informed about what's happening on the ward and have access to all the information they require. This includes general information about the ward and staff, and also specific information about their own care and treatment plan. This is an essential step to empower patients to be involved in their own care and treatment, as patients cannot meaningfully participate in decision-making without being adequately informed. It is particularly crucial that all patients, whether they are detained or in the hospital voluntarily, are fully informed about their legal and human rights and are aware of how to exercise these rights. This should be proactively offered to patients rather than waiting for patients to ask for the information.

The provision of psychological therapies across the hospital should be substantially increased to meet the patient demand and address the lack of access reported by many patients. This is a necessary and essential step to improve the patient experience and the standard of care in the hospital. The services of the clinical psychology team should be proactively offered to patients to ensure that all patients know what services and treatment options are available in the hospital.

Art and music therapy in the hospital is very highly valued by patients and so these services should be maintained and expanded upon. Both individual sessions and group sessions should be made available to patients.

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There should be a clearer route to discharge, and patients should be made more aware of what they have to do to move on from hospital. Patients should be fully involved in the discharge planning process to make sure they feel prepared to leave, including visiting their future accommodation. The experiences of patients who are readmitted to hospital after being discharged should be explored to identify how the discharge process can be improved to support patients to maintain their recovery after leaving hospital.

Attention should be paid to the issue of loneliness in the hospital. Many patients report feeling lonely and socially isolated, and this has a strong negative effect on people. Social interaction is very important for people in hospital and more should be done to help patients socialise. Increased group activities on the ward and staff engagement with patients are important first steps to tackling this issue.

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Acknowledgements

Referenced Documents

Bombard, Y., Baker, G.R., Orlando, E. et al. Engaging patients to improve quality of care: a systematic review. Implementation Science, 13, 98 (2018). https://doi.org/10.1186/s13012-018-0784-z

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77–101. DOI: 10.1191/1478088706qp063oa

European Court of Human Rights, *Guide on Article 8 of the European Convention on Human Rights: Right to respect for private and family life, home and correspondence.* 2020. Available at: https://www.echr.coe.int/documents/guide_art_8_eng.pdf [accessed 11 January 2021]

United Nations General Assembly, *Convention on the Rights of Persons with Disabilities*. 2006. Available at: https://www.refworld.org/docid/4680cd212.html [accessed 11 January 2021].

United Nations Committee on the Rights of Persons with Disabilities, *General Comment No. 1, Article 12: Equal recognition before the law*. 2014. Available at: https://www.ohchr.org/en/hrbodies/crpd/pages/gc.aspx [accessed 11 January 2021].

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Appendix 1 – Patient Experience Questionnaire

Part 1: In this part we would like you to read 15 statements and tell us how much they describe your own personal experience of being here. Each statement is rated on a 5-point scale of strongly agree to strongly disagree. **Please tick one response for each question**.

You can also add extra comments below each question if you want, and there's more space at the end of the survey if you need it. You don't have to answer any questions you don't want to.

1. I feel safe being here.

○	○	○	○	○
Strongly Agree	**Agree**	**Neither**	**Disagree**	**Strongly Disagree**

2. I feel being here is helpful for me.

○	○	○	○	○
Strongly Agree	**Agree**	**Neither**	**Disagree**	**Strongly Disagree**

3. I have felt discriminated against while being here.

○	○	○	○	○
Strongly Agree	**Agree**	**Neither**	**Disagree**	**Strongly Disagree**

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4. My human rights are respected here.

Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
○	○	○	○	○

5. I am given enough information about my care and treatment.

Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
○	○	○	○	○

6. I have been meaningfully involved in the development of my care and treatment plan on an ongoing basis.

Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
○	○	○	○	○

7. I am meaningfully involved in the decisions and discussions which affect me.

Strongly Agree	Agree	Neither	Disagree	Strongly Disagree
○	○	○	○	○

8. I have been given enough opportunities to discuss my medication.

○	○	○	○	○
Strongly Agree	**Agree**	**Neither**	**Disagree**	**Strongly Disagree**

9. Conditions in the hospital have been more restrictive than necessary.

○	○	○	○	○
Strongly Agree	**Agree**	**Neither**	**Disagree**	**Strongly Disagree**

10. I feel lonely or socially isolated in the hospital.

○	○	○	○	○
Strongly Agree	**Agree**	**Neither**	**Disagree**	**Strongly Disagree**

11. The staff here treat me with compassion.

○	○	○	○	○
Strongly Agree	**Agree**	**Neither**	**Disagree**	**Strongly Disagree**

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12. The staff involved in my care and treatment are approachable when I want to speak with them.

| ○ Strongly Agree | ○ Agree | ○ Neither | ○ Disagree | ○ Strongly Disagree |

13. I feel bored on the ward.

| ○ Strongly Agree | ○ Agree | ○ Neither | ○ Disagree | ○ Strongly Disagree |

14. I have as much access to psychological therapy and clinical psychology as I would like.

| ○ Strongly Agree | ○ Agree | ○ Neither | ○ Disagree | ○ Strongly Disagree |

15. I have as much access to other therapeutic activities as I would like (Examples include art and music therapy)

| ○ Strongly Agree | ○ Agree | ○ Neither | ○ Disagree | ○ Strongly Disagree |

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Part 2: In this part we are interested in your thoughts about your overall experience in your own words.

16. What things, if any, are making it more difficult for you here?

17. What aspects, if any, of your care and treatment are particularly good?

18. What 2 – 3 words would you use to describe what it's like to be here?

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19. How did you complete this survey?

Alone ○

With a member of staff ○

With a member of the Patients Council ○

With someone else (Please state who) ○

This is the end of the survey. We will feed back the results to you next month.

You can use the space below or ask for more paper if there is anything else you want to tell us about your experience, or if you need more space to answer the questions. You can also contact the Patients Council if you'd rather speak with someone.

Thank you for taking part 🙂