Advance statements in Scotland

Statistical Monitoring

July 2021

Our mission and purpose

Our Mission

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

Our Purpose

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

Our Priorities

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

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

Our Activity

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

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Executive summary

Advance statements provide a mechanism for a person to express how they wish to be treated and how they do not wish to be treated if they were to become unwell due to a mental disorder[1] and have impaired decision making about medical treatment. Professionals working with the person must have regard to the wishes expressed in their advance statement.

There were concerns expressed in the Scottish Government's review of the Mental Health Act in (known as 'the McManus Review') about the lack of uptake of advance statements. However, there have not been any estimates on prevalence until this report.

In this report, we report a prevalence figure for advance statements based on information that the Mental Welfare Commission ('the Commission') holds from T3 certificates for people who are detained under the Mental Health Act. A T3 certificate is a statutory safeguard protecting the rights of people who do not or cannot consent to treatment for mental disorder. They are completed by independent senior psychiatrists who have undertaken special training organised by the Commission in order to undertake this role. The T3 certificate authorises the treatment for people who do not or cannot consent to the treatment that their own doctor thinks that they should have. This is a key group of people to explore the uptake of advance statements in, as because they are detained under the Mental Health Act, they have significantly impaired decision making ability with regards to treatment for mental disorder. They might benefit from having had the opportunity to set out in an advance statement what they would want and would not want in these circumstances.

We looked at information that the Commission holds for 4,721 people who were receiving care and treatment under a T3 certificate between 29 June 2017 and 1 December 2020 to establish how many had advance statements.

We also looked at the characteristics of people, such as age, gender and previous experience of treatment under the Mental Health Act, to see whether there were differences between those who had and those that did not have an advance statement. This will help with understanding if there are particular groups that should be targeted to be encouraged to make an advance statement.

Key findings

- Of all people who received treatment under a T3 certificate, only 309 (6.6%) had an advance statement. The remaining 4,399 people (93.4%) did not have an advance statement.

- When we compared across the three years that we had complete information for (2018-20), the proportion of individuals receiving treatment who had an advance

[1] The Mental Health (Care and Treatment) Act 2003 uses the term 'mental disorder'.

statement was similar in each year (7.2%, 6.9% and 7.3%), respectively. This indicates no change over that time period.

- Compared to those who did not have an advance statement, those who had one were younger, a higher proportion were male (62.8% vs 56.1%), and a slightly higher percent were from the most deprived areas in Scotland (61.5% vs 55.4%), defined as category 1 and 2 of the Scottish Index of Multiple Deprivation (SIMD) quintiles.

- Those who had an advance statement had more previous episodes of compulsion under the Mental Health Act than those who did not have one.

- Among people who had an advance statement, 36.9% had their advance statement overridden.

- When we compared characteristics of people who had an advance statement that was overridden with those whose advance statement was not in conflict with the treatment being recommended, we found a higher proportion of overrides for those from the most deprived areas (SIMD category 1), for women, for those who were White Scottish or other White ethnicities, and for those who had a higher number of previous episodes.

- When we compared the characteristics of people treated under a T3 who had an advance statement with the characteristics of people on our own advance statement register, we found that a higher percentage of people on the register were in the age group 65 years and older, were female, and fewer were living in the most deprived areas of Scotland.

Recommendations

1. We suggest that health boards take steps to promote advance statements for people using their mental health services through indicating at what point in the relevant care pathways advance statements should be discussed, including considerations of what support is available for people who choose to pursue making one. Advance statement registration with the Commission should be integral to the relevant pathway.

2. Quality Improvement Teams at health boards and the research community may wish to consider the utility of undertaking further tests of change/research to establish the optimal moment in a person's contact with mental health services to make an advance statement. Involvement of carers and the named person in this process also needs to be fully considered.

3. As the Commission's advance statement register only records that one exists and where it is kept and what treatments are overridden and what is deemed not in conflict with the individual's wishes, it is difficult to assess their content. We recommend that the Scottish Mental Health Law Review (SMHLR) considers whether it would be helpful

to distinguish between an advance statement to refuse treatment from wishes about receiving specific treatments. This would be in keeping with the distinction between refusing treatment and requesting treatment in the more general sense.

4. We also ask that the SMHLR consider whether a new mental health law should require that people are offered the opportunity of developing an advance statement when a person completes an episode of a relevant compulsory treatment or at an appropriate time following this. The current low uptake we describe, despite 15 years of advance statements in Scotland, suggests the need for more focussed intervention to increase the uptake.

5. We note the findings from the previous Scottish Government review on the low uptake. We consider that a competently made advance refusal for a specific treatment should have a higher bar associated with any override of this including greater scrutiny. This may address the concern that an advance statement currently can be too easily overridden. Such considerations would put the UNCRPD principle of respecting the rights, will and preference of a person with disabilities at the heart of a new act in a demonstrable way.

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Introduction

Advance statements are written statements made by a person when they are well, setting out the care and treatment they would prefer or would dislike should they become mentally unwell in the future.

Where a person has written an advance statement it will come into force if the person becomes too unwell to make decisions about their treatment and is receiving compulsory treatment under the Mental (Care and Treatment)(Scotland) Act 2003 ('the Mental Health Act'). It must be read by the doctor or clinician making decisions about the person's treatment. While an advance statement can be overridden, there are safeguards in place to ensure that the override is reviewed, and the professionals involved have to justify their decision.

Advance statements should be a powerful way of ensuring that people with mental ill health are listened to and have their human rights respected. The Mental Welfare Commission ('the Commission') supports advance statements and ran an awareness raising campaign about them in 2015 supported by the then minister for mental health.

Health boards are responsible in the legislation for promoting advance statements. Since 2017, the Commission has kept a register of advance statements, but we know it is incomplete and that all advance statements are not being registered centrally. Previous work undertaken by the Scottish Government Review Group in 2009 (known as 'the McManus Review') suggested that the uptake of advance statements had been low.

In this report we explore this further and estimate the prevalence of advance statements for detained people who cannot consent or do not consent to treatments. This is a group that would benefit from having an advance statement.

The Law

The term 'advance statement' refers to written statements, made under the Mental Health Act, about treatment for mental disorder as defined in the Mental Health Act. An advance statement is written when a person has capacity to make a decision on the treatments they want or do not want. The treating psychiatrist must have regard to the advance statement and must inform key individuals important to the person and organisations such as the Commission if they override someone's advance statement.

Advance statements only apply to treatment. People can set out other information that will help staff take care of them in a personal statement. This can include who to contact if they become ill, information about physical health, dietary requirements or spiritual needs, or practical information about looking after the person's home. Under the principles of the Mental Health Act, that personal statement must be taken into account when decisions are made about a person's care. *Advance Statements provide a safeguard for families and carers who may be excluded from the care of an individual during an acute period of illness. They should be informed about how advance statements can provide safeguards during periods of ill health. Letting close family or friends know about advance statements might also help to*

prevent the fracturing of vital relationships with those who might provide support for the individual in the community.

The Mental Health Act sets out criteria under which an advance statement can be made, how it should be witnessed and what should happen when it is overridden. The relevant parts of the Mental Health Act are sections 275 and 276, and there are accompanying regulations.

The Code of Practice for the Mental Health Act makes the presumption that an individual who writes an advance statement will already have experience of treatment (Scottish Government, 2005). Most but not all people who receive care and treatment under the Mental Health Act will have had some experience of treatment from mental health services.

> *"Section 274 and 276 of the Mental Health Act enable a patient to make an advance statement. This is a written statement setting out how they would wish to be treated, or wish not to be treated, for mental disorder should their ability to make decisions about treatment for their mental disorder become significantly impaired as a result of their mental disorder."*

Research on the use of advance statements

There has been limited research on advance statements in Scotland. Past research has looked at patients' views and understanding of advance statements. A small study conducted over a six-month period in a lithium clinic in Paisley in 2005 found that only five of the 58 patients had heard of an advance statement. After providing information, 59% of the 27 patients who took part in this part of the study said they understood what advance statements were and 70% said they would consider creating one (Foy *et al.*, 2007).

A thematic analysis of 55 advance statements presented to the Mental Health Tribunal for Scotland over an eight-month period in 2007 showed that 96% of the statements included at least one specific treatment refusal e.g. 42% of statements included refusal of electroconvulsive treatment (ECT). On the other hand, some statements also contained requests for particular medications (45%). Just over half (55%) of statements contained wider information than medical treatment, including setting of care and other supports. The authors of this work concluded that the format of advance statements did not always follow the guidelines on creating these (Reilly and Atkinson, 2010).

The McManus review identified that there was a lack of uptake on advance statements, although the review did not have an actual prevalence estimate. They identified that most people had not heard of them, didn't know how and when to create one, and what should be written in an advance statement. Some people felt that what they would write in an advance statement would not be regarded (Scottish Government Review Group 2009, p8-9).

Scotland is not alone in failing to fully embed mechanisms to ensure a patient's voice is heard at the time when they may have reduced capacity to express their views on medical treatment for mental disorders. In England and Wales, a national survey of 544 people diagnosed with a bipolar illness found that only 5.0% of people had made a written advanced decision to refuse treatment (ADRT), which is a provision under the Mental Capacity Act 2005 in England and Wales that allows people to specify, when they have capacity, what treatments they do not want should they lose capacity to make a decision on that treatment (Morriss *et al.*, 2017).

Research from the US has also indicated that the prevalence is low, with 7% of people receiving treatment for schizophrenia and related disorders in North Carolina reporting that they had made a psychiatric advance directives (PAD) (Swanson *et al.*, 2003). In a larger US study across five US states involving 1,011 psychiatric outpatients the prevalence of having completed a PAD ranged from between 4% to 13% (Swanson *et al.*, 2006).

This report

To date there has been no estimate on the prevalence of advance statements in Scotland for any group of people who would benefit from one.

In this report we use the Commission's data to report on the prevalence among people who were detained under the Mental Health Act and were receiving care and treatment authorised

by a designated medical practitioner (DMP).[2] We provide more details on how we did this below.

We also look at some of the characteristics of the people who have an advance statement to see if there are any differences between those who have made one and those who haven't. This will help with understanding if there are particular groups that health boards and professionals should target to promote making an advance statement.

[2] A DMP is a senior psychiatrist appointed by the Mental Welfare Commission for Scotland who reviews the appropriateness and legality of treatment for people who are subject to compulsory powers and who do not consent or cannot consent to treatment after a period of two months and for other treatments that require additional safeguards such as ECT.

What we did

Information on T3 forms

The Commission has a duty to monitor the use of the Mental Health Act and to promote best practice. In that role, all T3 certificates that are filled out by a DMP under s237(3) and s240(3) are sent to the Commission. These authorisations come in two types of forms, T3A and T3B certificates (see Box 1).

A T3 certificate is used for authorising medical treatment where a person does not or cannot consent to treatment for mental disorder. Detained people being treated under a T3 certificate may benefit considerably from having made an advance statement stating what they would prefer or do not want. The most common use of a T3 certificate is for medication given beyond two months since the start of treatment under compulsion (see Box 1).

Box 1. Types of T3 certificates

A **T3A certificate** covers the treatments of electro-convulsive therapy (ECT), vagus nerve stimulation (VNS) and transcranial magnetic stimulation (TMS).

A **T3B certificate** covers any medication (other than the surgical implantation of hormones) given for the purpose of reducing sex drive, any other medication given beyond a period of two months since the start of compulsory treatment, or the provision, without consent of the patient and by artificial means, of nutrition to the patient.

The DMP has to discuss the treatment with the person and with their named person. If it was impracticable to do so, they need to state reasons why. The DMP also has to complete, as far as it is practicable to ascertain, whether or not the person has an advance statement and if the decision they made to authorise or not authorise treatment is in conflict with the wishes specified in that advance statement. If the advance statement is in conflict with the decision made to authorise or not authorise treatment, this is referred to as an advance statement override. The Commission monitors advance statement override notifications and we check that the treatment decision was necessary, and that adequate reasons have been given for this.

On the T3 form, the DMP fills out the date of the advance statement and details of all treatments that are authorised that are in conflict with the advance statement and why. Also, when treatment is not authorised and conflicts with an advance statement asking for this particular treatment that has to be detailed too. A T3B for medication can be authorised for up to three years, after which a new one is required, unless there is a clinical need for earlier review and DMPs have discretion to set the review period as they see fit.

Analysis of T3 information

We looked at all T3 certificates received from 29 June 2017[3] to 1 December 2020. We summarised demographic characteristics of people who received treatment, including age, gender, ethnicity, sub-category of mental disorder from the Mental Health Act's definition (s328)[2], previous admissions under the Mental Health Act or the Criminal Procedure (Scotland) Act 1995 ('the Criminal Procedures Act') and deprivation according to the Scottish Index of Multiple Deprivation (SIMD). We also summarised information about health board of treatment, including the State Hospital, which is a high security hospital which as a national service is legally regarded as a special health board.

We have incomplete information in relation to ethnicity and postcode (to defined SIMD). For ethnicity, we had no information (due to blank ethnicity forms with missing data) for 658 individuals (14%) and for 382 (8%) ethnicity was not provided when asked. We will be reporting on ethnicity and mental health later this year and will make recommendations to improve the incomplete recording of ethnicity within that report. For postcode, we were unable to match the information with SIMD for 648 individuals (14%) due to either a missing/erroneous postcode on the form or because the postcode was a hospital rather than the home address of the person. We are also working on ways to improve this data.

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[3] The Commission began to collect information regarding presence of an advance statement in relation to treatment under a T3 when the Mental Health (Scotland) Act 2015 went live in July 2017.

[2] These are 'mental illness', 'personality disorder' and 'learning disability' as referred to in the Mental Health Act.

What we found

Counting individual T3s

Over the time period we looked at we received 7,020 T3 certificates. Since a person could be treated under a T3 on more than one occasion, and we wanted to understand how many people who receive treatment have an advance statement, we only counted each person once. To do that, we looked at all T3s for each person over the time period and selected one T3 for each person based on what was said about an advance statement, which was either:

1. no advance statement recorded for the individual;
2. an advance statement was recorded, which was not in conflict with the treatment; or
3. an advance statement was recorded, which was overridden.

For each person we counted the T3 instance that appeared earliest in the time period with the greatest impact regarding an advance statement. For example, if a person had three T3 certificates: 1) one where advance statement recorded and not in conflict with the treatment in 2017, 2) one where advance statement recorded and overridden in 2018, and 3) one where an advance statement was recorded and overridden in 2019 we would count the second of those T3s for this person as the advance statement was overridden and it was the earliest time that this had happened.

Using this process, there were 4,721 people who had a T3 certificate recorded in the time period. For 13 people there was no information recorded about an advance statement so we excluded them from our analysis. The total number of people that are included in the work that this report describes is therefore 4,708.

Who has an advance statement?

Of all of the people who received treatment under a T3 certificate, 309 (6.6%) had an advance statement.

When we compared across the three years that we had complete information for (2018, 2019 and 2020), the proportion of people receiving treatment who had an advance statement was similar at 7.2%, 6.9% and 7.3%, respectively.

The median age of people who had an advance statement was slightly younger than those who did not have an advance statement (47 years and 54 years, respectively) and a slightly higher percent were male (62.8% and 56.1%, respectively). All characteristics of people are presented in Appendix Table 1.

In the group who had an advance statement, compared to those who didn't, a higher percentage lived in an area in SIMD category 1 (36.2% and 32.7%, respectively) and 2 (25.3% and 22.7%, respectively), which are the most deprived areas in Scotland.

Most of those with an advance statement (as well as those who did not have one) were White Scottish (72.2% and 74.4%, respectively), but a higher percent of those with an advance statement were White Other British (8.9% and 6.8%, respectively) and White Other (6.3% and

4.1%, respectively). This compares to the general population where 84.0% are White Scottish, 7.9% are White Other British and White Other (4.2%) from the 2011 census data.

Of the subcategories from the s328 definition of a mental disorder we found a higher proportion of people with an advance statement who had both ‘mental illness and personality disorder’ (8.8%) compared with those that did not have an advance statement (2.9%) and a lower proportion of those who made an advance statement had ‘mental illness’ compared to those who did not have an advance statement (80.3% and 88.8%, respectively).

We found that the median number of episodes under the Mental Health Act or the Criminal Procedure Act for individuals who had an advance statement was higher than for those who did not have one (five episodes and two episodes, respectively).

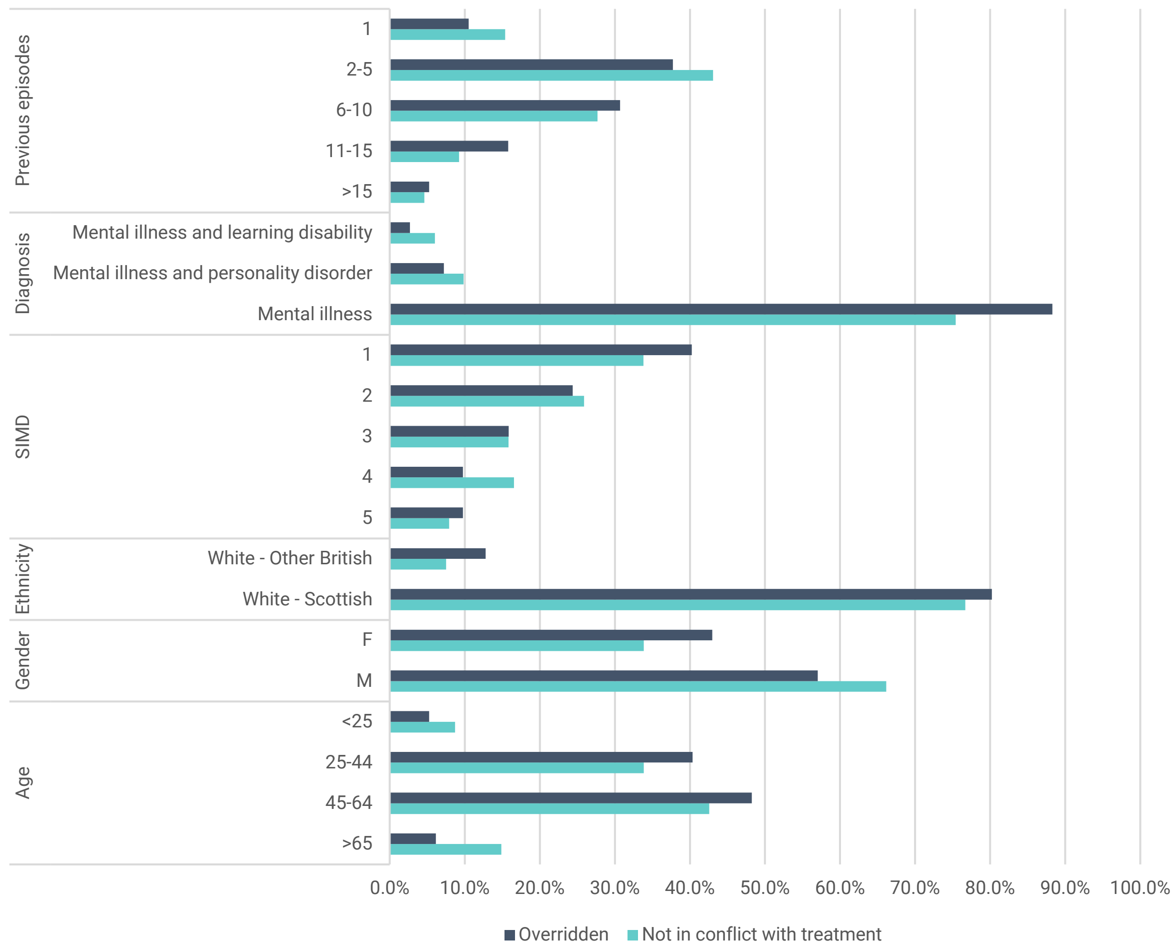
Advance statements overridden or not in conflict with treatment

We wanted to compare if there were any differences in the characteristics of those who had an advance statement that was not in conflict with the treatment they were receiving; and those who had their advance statement overridden.

Of the 309 people with an advance statement, 114 people (36.9%) had their advance statement overridden and for the remaining 195 (63.1%) the advance statement was not in conflict with the treatment

We found that there was a higher proportion of overrides among people who had a mental illness as a single diagnosis, those from the most deprived areas (SIMD category 1), females, and for those who had multiple previous episodes (6–10 and 11–15) (Figure 1). Within the group who had their advance statements overridden, a higher proportion were White Scottish (80.2% vs 76.7%) and White Other British (12.8% vs 7.5%), compared to those whose advance statement was not in conflict with the treatment. All other ethnicities had too low numbers to present data here. Of note, gender is only recorded as male or female in the data sets that relate to the Mental Health Act. We are working with stakeholders so that other genders can be recorded.

Figure 1. Individual characteristics among individuals whose advance statement was not in conflict with the treatment and those whose advance statements were overridden



Note that any ethnicity other than White Other British and White Scottish, diagnoses other than mental illness as single diagnosis or with personality disorder or learning disability have been excluded due to small numbers[4]

When we looked at the proportion of all individuals with advance statements by the health board they were treated in we found some differences in how many advance statements were not in conflict with the treatment and those overridden (Figure 2). In half of the mainland health boards the percent of overrides of advance statements was lower than the average overall. In the remaining health boards the proportion of overrides was higher than average and Forth Valley had the highest proportion of overrides. However, it should be noted that this relates to a total of only 12 advance statements. Similarly, the total number of advance statements in the Borders and in Dumfries and Galloway were less than 10.

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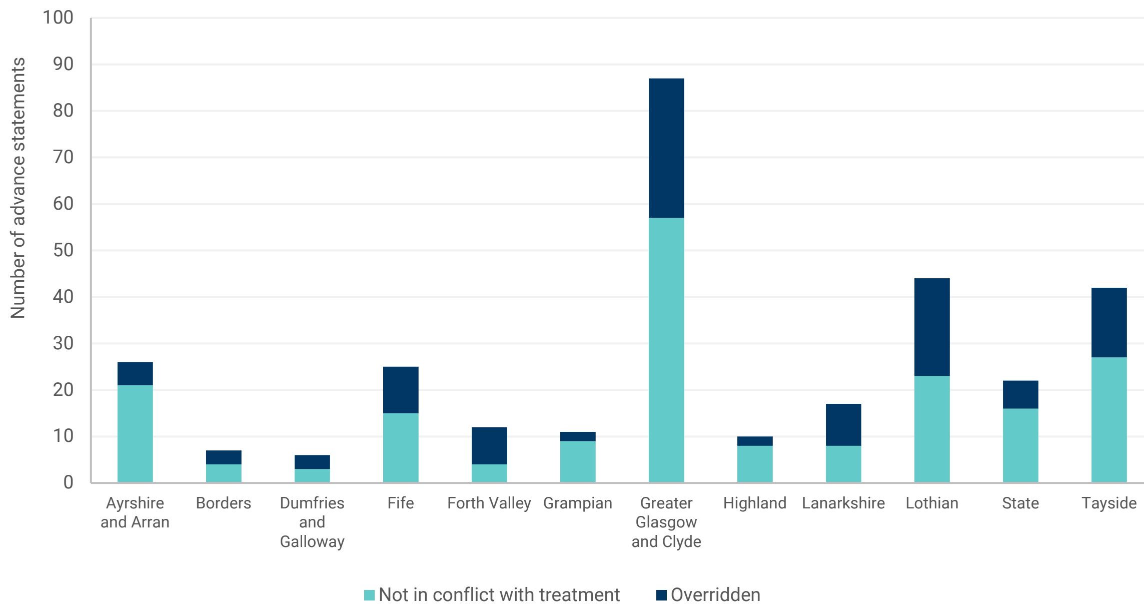
[4] We follow Public Health Scotland's *Statistical Disclosure Control Protocol* and exclude numbers in categories with n<5 or categories where a small number can be implied from another cell. We therefore suppress or exclude data where necessary.

Figure 2. Number of advance statement that were overridden or not in conflict with treatment, by health board



Comparison with the advance statement register

The Commission has kept a register of advance statements since 2017. When a person writes an advance statement, the health board is required to tell us that this has been done and where it is being held. We are not informed about the content of the advance statement, simply that one is registered for the person.

Figure 3 shows the number of advance statements with a starting date since 1 July 2017 registered with the Commission. Between the first full year of data (2018) and the next (2019) there was a 40% increase in number of advance statements. However, there may have been an impact of Covid-19 as there was a 65% decrease in advance statements with a date in 2020 (n=111) although the numbers were declining from August 2019.

It is possible that the various systems that are involved in processing advance statements at the health board level have not caught up and these figures underreport the true numbers in 2020. On the other hand, during the pandemic there has been a focus on advance planning in the broadest sense and the focus of the pandemic may therefore represent a key moment to embed advance planning into clinical practice generally and advance statements specifically.

Figure 3. Advance statements registered with the Commission

Source: The Commissions advance statement register as of 18 February 2021

Not everyone who has an advance statement has had this registered with the Commission and those who have an advance statement registered may not have been subject to any compulsory powers. We have recommended that health boards put in place processes so that when advance statements are created they are registered with us.

We wanted to see if there were any differences in the characteristics (such as age or gender) between: i) people who have written an advance statement that has been registered with the Commission, and ii) people who were treated under a T3 certificate who we found had an advance statement.

By exploring if there are differences between these two groups we may be able to identify if certain groups are under-represented on the register compared to people who are subject to compulsion receiving treatment authorised by a T3 certificate. This is the first attempt to understand the incompleteness of the Commission's register.

We have less information about individuals who register an advance statement with the Commission than information that we gather from T3 certificates, so we here we can only look at age, gender, and SIMD category. Ethnicity is not recorded for people on the advance statement register.

As of 18 February 2021 there were 863 advance statements recorded in our register, relating to 706 individuals. The median age was similar for people who do not or cannot consent to treatment and the register (47 years and 49 years, respectively), but Figure 3 shows that a higher percentage of people on the register were in the age group 65 years and older (28% and 12%, respectively).

A higher percentage of people on the register were women (44% and 37%, respectively) and fewer people on the register were living in SIMD quintile 1 (24% and 33%, respectively).

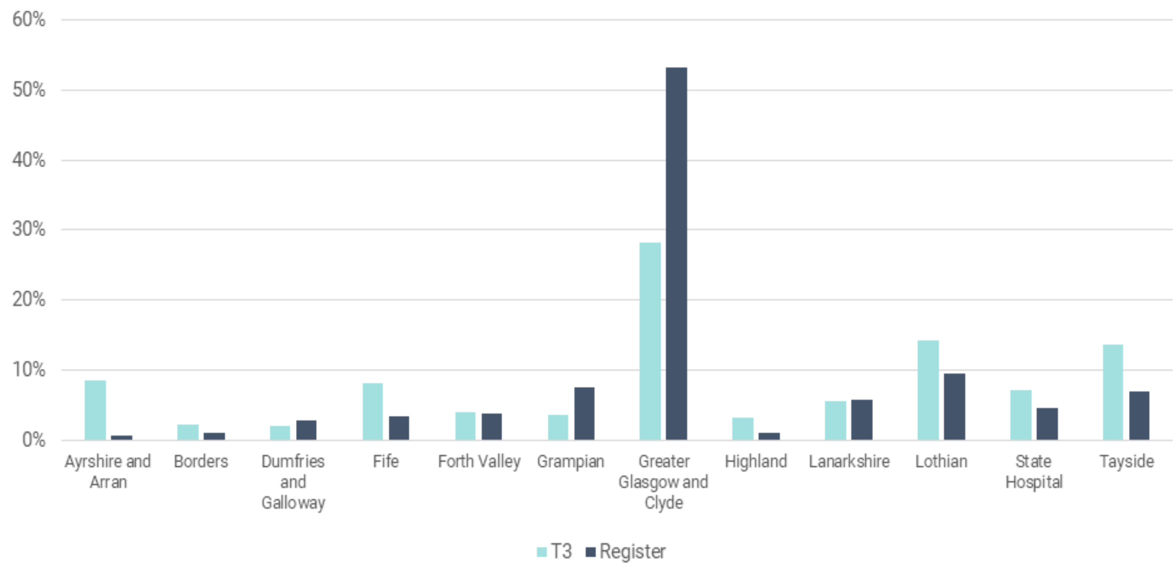
Figure 4. Comparison of characteristics of individuals treated under a T3 who had an advance statement and individuals who have registered an advance statement

Note that SIMD data was missing for 88 of individuals with an advance statement treated under a T3 certificate

We also looked at the locations of people who received treatment and those on the register, by the health board of treatment and health board the advance statement is registered with. We cannot compare these with certainty, though, as an individual could receive treatment in a difference health board to where their advance statement was registered. We excluded advance statements registered with private hospitals (n=56) and island health boards.

Compared to the register, more people were represented for treatment under a T3 certificate in Ayrshire and Arran, the Borders, Fife, Highland, Lothian, The State Hospital and Tayside. The proportion of advance statements registered in Greater Glasgow and Clyde was significantly higher than what we observed among individuals receiving treatment (53% and 28%, respectively). This is of course, in line with that about one third of all detentions each year are in Greater Glasgow and Clyde and similarly a large proportion of T3s were in this health board (see Appendix, Table 1).

Figure 5. Distribution of advance statements individuals unable to consent/refusing treatment and on the advance statement register, by health board



Note that island boards and private hospitals excluded.

What this means

In this report, we have shown that among people receiving care and treatment with a T3 certificate under s237(3) and s240(3) of the Mental Health Act, only 6.6% had an advance statement.

While we still cannot say how many people with mental illness, and who may benefit from writing an advance statement, have one, it is a first national estimate of how many people have taken anticipatory action about their care and treatment and it reflects a group that might benefit particularly from having one.

Health boards have had a duty to promote advance statements since 2017. However, in the three years we had data we did not see any difference in the percentage of individuals receiving treatment who had an advance statement.

The proportion of people who do not or cannot consent to treatment who have an advance statement is similar to that found in a study of advance decision to refuse treatment in writing in a national survey among people with bipolar disorder in England and Wales, which was 5% (Morriss *et al.*, 2017). In our report we did not have further information on the specific diagnosis to further contrast whether there are any differences between individuals with different mental disorders.

Reasons for the low uptake of advance statements include a lack of awareness and understanding of the process, confusion of what should be included, lack of belief that the advance statement will be upheld, and difficulty in contemplating being unwell again once in recovery (Scottish Government, 2009). There is likely an optimal time during recovery when it would be most reasonable for a person to create an advance statement, before they may become unwell again but not too far into their period of stability.

Although the State Hospital only constituted 7.1% of people unable to consent or refusing treatment, it had the highest proportion of individuals overall with an advance statement. Of the 76 patients treated in the State Hospital, 28.9% had an advance statement. As a high number of individuals treated at the State Hospital have an advance statement in place we will continue to look further into promotion of advance statement in particular groups such as high secure care and forensic settings to see if anything can be learned from this in terms of health education and engagement.

We found a higher percentage of individuals who had an advance statement who had more previous episodes under the Mental Health Act or the Criminal Procedure Act. While it is reassuring to see that those who had multiple previous episodes to greater extent had made an advance statement, there was a higher percent of overrides in the group who had six or more previous episodes. This may reflect greater complexity of this group or experience of treatment that did not work well or led to side effects which may impact on the content of the advance statement. However, we are unable to draw conclusions of why this may be. Further work is needed to better understand why we see this difference.

As a lack of belief that an advance statement will be upheld has been suggested as a reason for low uptake (Kelly, 2016), and reasons for advance statements being overridden are important to take into consideration. We have here shown that almost 40% of people with an advance statement had it overridden in relation to care and treatment for people who do not or cannot consent to treatment. The differences we have described here in percentage who had their advance statements overridden based on age, gender, diagnosis, and health board of treatment require further work to get a better understanding of how the content of advance statements in these groups differ, leading to them not being upheld. We note that work into the content of advance statements in Scotland is limited and we have only identified one study which explored the content in detail (Reilly and Atkinson, 2010).

The content of advance statements can be both refusals for a treatment and a statement of wishing a particular treatment. The distinction between a decision to refuse treatment and an expressed wish to receive something has legal and ethical significance. Current legislation around advance statements does not reflect this distinction well.

The Commission's view is that an advance statement is a valuable tool in facilitating patient participation in treatment and recovery, meaning overriding should be carefully thought through (Mental Welfare Commission for Scotland, 2017). Families and carers should also be informed about how advance statements can provide safeguards during periods of ill health. The Commission will continue to monitor and report on the numbers of advance statements registered with ourselves but we also intend to include inequalities indicators as part of our monitoring activity.

Limitations of this work

Our report only looked at individuals who had received care and treatment under a T3 certificate and therefore does not tell us about how many people have made an advance statement among all individuals with mental illness who might benefit from one. This does not represent all individuals who have been detained under the Mental Health Act for a shorter period (for example under an emergency detention).

Our data is incomplete for ethnicity and postcodes for many individuals. We are continuing to work to improve the completion of data to ensure our records are as complete as possible, but the findings need to be interpreted with this in mind

As we created a selection process to present information relating to the number of individuals rather than the number of T3 certificates it means that some individuals may have had different experiences in relation to an advance statement being considered not in conflict or overridden on an earlier occasion. We noticed that this was the case for a few individuals and the information presented should be interpreted with this in mind.

Recommendations

1. We suggest that health boards take steps to promote advance statements for people using their mental health services through indicating at what point in the relevant care pathways advance statements should be discussed, including considerations of what support is available for people who choose to pursue making one. Advance statement registration with the Commission should be integral to the relevant pathway.

2. Quality Improvement Teams at health boards and the research community may wish to consider the utility of undertaking further tests of change/research to establish the optimal moment in a person's contact with mental health services to make an advance statement. Involvement of carers and the named person in this process also needs to be fully considered.

3. As the Commission's advance statement register only records that one exists and where it is kept and what treatments are overridden and what is deemed not in conflict with the individual's wishes, it is difficult to assess their content. We recommend that the Scottish Mental Health Law Review (SMHLR) considers whether it would be helpful to distinguish between an advance statement to refuse treatment from wishes about receiving specific treatments. This would be in keeping with the distinction between refusing treatment and requesting treatment in the more general sense.

4. We also ask that the SMHLR consider whether a new mental health law should require that people are offered the opportunity of developing an advance statement when a person completes an episode of a relevant compulsory treatment or at an appropriate time following this. The current low uptake we describe, despite 15 years of advance statements in Scotland, suggests the need for more focussed intervention to increase the uptake.

5. We note the findings from the previous Scottish Government review on the low uptake. We consider that a competently made advance refusal for a specific treatment should have a higher bar associated with any override of this including greater scrutiny. This may address the concern that an advance statement currently can be too easily overridden. Such considerations would put the UNCRPD principle of respecting the rights, will and preference of a person with disabilities at the heart of a new act in a demonstrable way.

References

Foy, J., MacRae, A., Thom, A. and Macharouthu, A. (2007), “Advance statements: Survey of patients’ views and understanding”, *Psychiatric Bulletin*, Cambridge University Press, Vol. 31 No. 9, pp. 339–341.

Kelly, B. (2016), *Mental Illness, Human Rights and the Law*, Royal College of Psychiatrists, available at: https://www.cambridge.org/core/books/mental-illness-human-rights-and-the-law/3425DD3394345F597DDEEB0EAF7CD49F (accessed 17 May 2021).

Mental Welfare Commission for Scotland. (2017), *Advance Statement Guidance: My Views, My Treatment*, available at: https://www.mwcscot.org.uk/sites/default/files/2019-06/advance_statement_guidancesep2018revision.pdf.

Morriss, R., Mudigonda, M., Bartlett, P., Chopra, A. and Jones, S. (2017), “National survey and analysis of barriers to the utilisation of the 2005 mental capacity act by people with bipolar disorder in England and Wales”, *Journal of Mental Health*, Taylor & Francis, Vol. 29 No. 2, pp. 131–138.

Reilly, J. and Atkinson, J.M. (2010), “The content of mental health advance directives: Advance statements in Scotland”, *International Journal of Law and Psychiatry*, Pergamon, Vol. 33 No. 2, pp. 116–121.

Scottish Government. (2005), *Mental Health (Care and Treatment) (Scotland) Act 2003: Code of Practice Volume 1*, available at: https://www.gov.scot/publications/mental-health-care-treatment-scotland-act-2003-code-practice-volume-1/.

Scottish Government. (2009), *Limited Review of the Mental Health (Care and Treatment) (Scotland) Act 2003: Report As Presented to Scottish Ministers March 2009*, available at: https://lx.iriss.org.uk/sites/default/files/resources/0084966.pdf.

Srebnik, D.S., Russo, J., Sage, J., Peto, T. and Zick, E. (2003), “Interest in psychiatric advance directives among high users of crisis services and hospitalization”, *Psychiatric Services*, Psychiatr Serv, Vol. 54 No. 7, pp. 981–986.

Swanson, J., Swartz, M., Ferron, J., Elbogen, E. and Van Dorn, R. (2006), “Psychiatric Advance Directives Among Public Mental Health Consumers in Five U.S. Cities: Prevalence, Demand, and Correlates”, *Journal of the American Academy of Psychiatry and the Law Online*, Vol. 34 No. 1.

Swanson, J.W., Swartz, M.S., Hannon, M.J., Elbogen, E.B., Wagner, H.R., McCauley, B.J. and Butterfield, M.I. (2003), “Psychiatric advance directives: A survey of persons with schizophrenia, family members, and treatment providers”, *International Journal of Forensic Mental Health*, Vol. 2 No. 1, pp. 73–86.

Appendix – Data tables

Table 1. Individual characteristics

Characteristic	Category	Advance Statement		Total (N=4,708)
		Yes (n=309)	No (n=4,399)	
Age (median, IQR)	–	47 (35–57)	54 (36–71)	53 (36–70)
Age (n=4,708)	<25	23 (7.4)	435 (9.9)	458 (9.7)
	25–44	112 (36.2)	1,125 (25.6)	1,237 (26.3)
	45–64	138 (44.7)	1,333 (30.3)	1,470 (31.2)
	≥65	36 (11.7)	1,506 (34.2)	1,541 (32.8)
Sex (n=4,708)	Male	194 (62.8)	2,469 (56.1)	2,663 (56.6)
	Female	115 (37.2)	1,930 (43.9)	2,045 (43.4)
Ethnicity (n=3,668)	White Scottish	171 (78.1)	2,837 (82.3)	3,008 (82.0)
	White Other British	21 (9.6)	258 (7.5)	279 (7.6)
	White Other	15 (6.8)	157 (4.6)	172 (4.7)
	Asian	5 (2.3)	97 (2.8)	102 (2.8)
	African, Caribbean or Black	*	*	66 (1.6)
	Other[a]	*	*	41 (1.0)
Health board (n=4,707)	Greater Glasgow and Clyde	87 (28.2)	1,441 (32.8)	1,528 (32.5)
	Lothian	44 (14.2)	806 (18.3)	850 (18.1)
	Tayside	42 (13.6)	407 (9.3)	449 (9.5)
	Fife	25 (8.1)	310 (7.0)	335 (7.1)
	Grampian	11 (3.6)	317 (7.2)	328 (7.0)
	Lanarkshire	17 (5.5)	275 (6.3)	292 (6.2)
	Forth Valley	12 (3.9)	259 (5.9)	271 (5.8)
	Ayrshire and Arran	26 (8.4)	172 (3.9)	198 (4.2)
	Highland	10 (3.2)	173 (3.9)	183 (3.9)
	Dumfries and Galloway	6 (1.9)	109 (2.5)	115 (2.4)
	Borders	7 (2.3)	72 (1.6)	79 (1.7)
	State Hospital	22 (7.1)	54 (1.2)	76 (1.6)
	Western Isles	*	*	*

SIMD (n=4,060)	1 (most deprived)	80 (36.2)	1,255 (32.7)	1,335 (32.9)
	2	56 (25.3)	871 (22.7)	927 (22.8)
	3	35 (15.8)	679 (17.7)	714 (17.6)
	4	31 (14.0)	593 (15.4)	624 (15.4)
	5 (least deprived)	19 (8.6)	441 (11.5)	460 (11.3)
Diagnosis (n=4,639)	MI	236 (80.3)	3,858 (88.8)	4,094 (88.3)
	MI and LD	14 (4.8)	234 (5.4)	248 (5.3)
	MI and PD	26 (8.8)	128 (2.9)	154 (3.3)
	LD	7 (2.4)	79 (1.8)	86 (1.9)
	PD	*	*	*
	MI, LD and PD	*	*	*
	LD and PD	*	*	*
Previous episodes (n=4,708)	Median (IQR)	5 (2–8)	2 (1–3)	2 (1–4)
	0	0	7 (0.2)	7 (0.1)
	1	42 (13.6)	1,962 (44.6)	2,004 (43.6)
	2-5	127 (41.1)	1,812 (41.2)	1,939 (41.2)
	6-10	89 (28.8)	426 (9.7)	515 (10.9)
	11-15	36 (11.7)	130 (3.0)	166 (3.5)
	>15	15 (4.9)	62 (1.4)	77 (1.6)

[a]Includes Mixed and 'Other'. MI: mental illness, LD: learning disability, PD: personality disorder.

*Suppressed due to n<5 or secondary suppression

Table 2. Characteristics based on override status

Characteristic	Category	Overridden	
		Yes (n=114)	No (n=195)
Age	Median (IQR)	46 (37–54)	48 (34.5–59)
Age (n=309)	<25	6 (5.3)	17 (8.7)
	25-44	46 (40.4)	66 (33.8)
	45-64	55 (48.2)	83 (42.6)
	≥65	7 (6.1)	29 (14.9)
Sex (n=309)	Male	65 (57.0)	129 (66.2)
	Female	49 (43.0)	66 (33.8)
Ethnicity (n=219)	White Scottish	69 (80.2)	102 (76.7)
	White Other British	11 (12.8)	10 (7.5)
	White Other	*	*
	Asian	*	*
	African, Caribbean or Black	*	*
	Other[a]	*	*
SIMD (n=221)	1 (most deprived)	33 (40.2)	47 (33.8)
	2	20 (24.4)	36 (25.9)
	3	13 (15.9)	22 (15.8)
	4	8 (9.8)	23 (16.5)
	5 (least deprived)	8 (9.8)	11 (7.9)
Diagnosis (n=294)	MI	98 (88.3)	138 (75.4)
	MI and PD	8 (7.2)	18 (9.8)
	MI and LD	3 (2.7)	11 (6.0)
	LD	*	*
	PD	*	*
	LD and PD	*	*
	MI, LD and PD	*	*
Previous episodes (n=309)	Median (IQR)	4 (3–9)	6 (2–8)
	1	12 (10.5)	30 (15.4)
	2-5	43 (37.7)	84 (43.1)
	6-10	35 (30.7)	54 (27.7)
	11-15	18 (15.8)	18 (9.3)
	>15	6 (5.3)	9 (4.6)

[a]Includes Mixed and 'Other'. MI: mental illness, LD: learning disability, PD: personality disorder.

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