

Institution: King's College London		
Unit of Assessment: 4		
Title of case study: Shaping the Mental Health Act by increasing service user autonomy		
Period when the underpinning research was undertaken: 2004 – 2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s):	Role(s) (e.g. job title):	Period(s) employed by submitting HEI:
Dr Gareth Owen	Reader	2007 – present
Mr Alex Ruck Keene	Visiting Senior Lecturer	2017 – present
Dr Larry Rifkin	Visiting Senior Lecturer	2015 – present
Dr Tania Gergel	Senior Research Fellow	2015 – present
Dr Lucy Stephenson	Clinical Research Associate	2017 – present
Professor Matthew Hotopf	Professor of General Hospital Psychiatry	1994 – present
Dr Claire Henderson	Clinical Senior Lecturer	2009 – present
Professor Sir Simon Wessely	Regius Professor	1991 – present
Period when the claimed impact occurred: 2014 – 2020		
Is this case study continued from a case study submitted in 2014? N		

1. Summary of the impact

The Mental Health Act (MHA) legislates the care of people with a severe mental illness, including detention and compulsory treatment. Concerns about rising use of detention and protecting human rights within the Act led to calls for reform, and in 2017 the UK Government commissioned an Independent Review of the MHA (IRMHA). The IRMHA drew upon the findings of King's researchers working in collaboration with charities and service users, and these fundamentally shaped the IRMHA's 2018 report, including specific recommendations to enable patients to plan for their own care and treatment. King's researchers then worked with Government to incorporate the recommendations into legislation (delayed by COVID-19, Government recommendations were published January 2021). Early implementation at South London and Maudsley NHS Foundation Trust has enabled people with severe mental illnesses to exercise new forms of autonomy before, during and after detention under the MHA, and provides an implementation model for other trusts. A partnership with the charity Bipolar UK has made documents freely available on its website to enable service users to access these new forms of autonomy, and a partnership with a service user artist has led to an exhibition of new work with autonomy at its heart.

2. Underpinning research

The Mental Health Act (MHA) is the UK legislation which covers the care and treatment of people with a severe mental illness, and under which a person deemed to be at risk of harm to themselves or other people may be detained against their will for treatment. 50,893 detentions were recorded in 2019 - 2020, although NHS Digital states not all detentions are recorded, so that number will be higher. For those detained compulsorily under the Act, basic personal liberties are removed, and it can invoke enormous emotional strain for mental health service users and their families. With one in four people experiencing a mental health disorder at some time in their life, the MHA has the potential to touch every family in the country. King's research below took place in a context of much needed reform: the NHS Mental Health Taskforce recommended a review of the MHA based on the rising number of detentions and the disproportionate use of detention on Black, Asian and minority ethnic (BAME) groups, and in October 2017, Prime Minister Theresa May announced an Independent Review of the Mental Health Act (IRMHA), to be chaired by King's Regius Professor of Psychiatry Sir Simon Wessely based on his extensive body of research in multiple areas of

mental health. The IRMHA drew upon King's research, including work commissioned by the review.

King's researchers highlighted the need to review mental capacity in the context of the MHA. King's researchers carried out detailed assessments of mental capacity and clinical characteristics in patients in 250 consecutive admissions to psychiatric hospitals under the MHA (1,2). 86% of those formally detained for compulsory treatment lacked the mental capacity to make decisions about their treatment. 60% of those patients who were admitted 'informally' – i.e. chose to be admitted voluntarily – lacked the proper capacity to make decisions about their treatment and care. For voluntary patients, feelings of having been coerced, and refusal of treatment, were more likely in the group of patients who lacked the proper capacity to make this decision. Building on this work, to address the public policy challenges that arise at the interface between mental health and mental healthcare, and human rights, in 2017 King's adopted a collaborative approach with service users, clinicians, policy makers and third sector organisations to form its Mental Health and Justice (MHJ) research project, recognising the importance of including all voices (3). The MHJ project was awarded £2.5 million by the Wellcome Trust.

King's researchers provided evidence that making decisions in advance about care is acceptable and feasible for service users. Advance decision making (ADM) in mental health (sometimes known as "advance directives") refers to making a decision about what happens during a future period of ill health. Although some patients outline advance directives about their care in the event of detention, the MHA did not require these to be acted upon. King's clinical trials in the early 2000s on crisis plans for compulsory treatment orders (4) informed later research by King's MHJ project, commissioned by the IRMHA, to develop a new model of ADM grounded in the lived experience of fluctuating mental capacity as well as in psychiatry, ethics and law (5). The model has since been developed, using focus groups, into the Preferences and Advance decisions for Crisis and Treatment (PACT) document and guidance materials fit for implementation studies in clinical services (6). One challenge is developing models of ADM which can be implemented where patients have fluctuating mental capacity. King's research in collaboration with the charity Bipolar UK surveyed service users on their own experiences and perceptions of ADM (7). 88% of those surveyed expressed a desire to be involved in the planning of their treatment for the event that they lose the capacity to make decisions, but only 36% had done so.

King's research examined whether Community Treatment Orders (CTOs) make a difference to mental health outcomes. CTOs mandate treatment for mental disorder in the community, and are made by a responsible clinician (usually a psychiatrist) and an approved mental health professional (usually a social worker). King's researchers systematically reviewed all international evidence on CTOs and showed that there was no good evidence that the introduction of CTOs makes a difference to hospitalisations or other outcomes (8).

3. References to the research

1. Owen, G., Richardson, G., David, A. S., Szmukler, G., Hayward, P. & Hotopf, M. (2008) Mental capacity to make decisions on treatment in people admitted to psychiatric hospitals: cross sectional study *BMJ (International Edition)*, 337, 7660. DOI: 10.1136/bmj.39580.546597.BE
2. Owen, G., Szmukler, G., Richardson, G., David, A. S., Hayward, P., Rucker, J., Harding, D. & Hotopf, M. (2009) Mental capacity and psychiatric in-patients, implications for the new mental health law in England and Wales *British Journal of Psychiatry*, 195, 3, 257-263. DOI: 10.1192/bjp.bp.108.059782.
3. Gergel T., Kabir, T. (2016) "Reframing a model – the benefits and challenges of service user involvement in mental health research" *Knowing and acting in medicine*. Ed Robyn Bluhm. Rowman & Littlefield Publishers: London
4. Henderson, C., Flood, C., Leese M., Thornicroft G., Sutherby K., Szmukler G. (2004) Effect of joint crisis plans on use of compulsory treatment in psychiatry: single blind randomised controlled trial *British Medical Journal*, 329(7458), 136. DOI: 10.1136/bmj.38155.585046.63

5. Owen, G., Gergel, T. L., Stephenson, L., Hussain, O., Rifkin, L. & Ruck Keene, A. C. E., (2019) Advance decision-making in mental health - suggestions for legal reform in England and Wales *International Journal of Law and Psychiatry*, 64, 162-177. DOI: 10.1016/j.ijlp.2019.02.002
6. Stephenson, L.*, Gergel, T*, Rifkin, L., Ruck Keene, A., Owen, G. (2020) Preparing for Mental Health Act reform with the 'PACT': an advance decision-making template for fluctuating mental capacity associated with mental health crises *International Journal of Law and Psychiatry*, 71, 101563. DOI: 10.1016/j.ijlp.2020.1015631
7. Hindley, G., Stephenson, L., Rifkin, L., Ruck Keene, A., Gergel, T. Owen, G. (2019) "Why have I not been told about this?": a survey of experiences of and attitudes to advance decision-making amongst people with bipolar *Wellcome Open Research*. DOI: 10.12688/wellcomeopenres.14989.2.
8. Churchill, R., Owen, G., Singh, S. & Hotopf, M., (2007) International Experiences of using Community Treatment Orders *Department of Health, London*

4. Details of the impact

King's research has been influential at every step of the process leading to the Government's White Paper published in January 2021 (publication delayed by COVID-19). King's researchers engaged in the IRMHA, chaired by King's Professor Sir Simon Wessely, and conducted work specifically commissioned to inform IRMHA's recommendations and subsequent proposed changes to the MHA.

King's research shifted the recommendations of the IRMHA towards recognising mental capacity and patient involvement in care. King's researchers, including those with lived experience, were key advisors to the Autonomy Group of the IRMHA, addressing a key service user concern: "*I felt a lot of things were done to me rather than with me*" [A1 p71, A2]. This Group used King's research (1,2,3,5; published subsequent to IRMHA meetings) to support recommendations on the provision of Advance Choice Documents (ACDs). These allow people to say how they want to be treated in the future and require doctors to record why treatment preferences are not followed. They were one of the IRMHA's key recommendations [A3]. The approach of King's MHJ project to conducting research which includes the voice of service users was noted in the IRMHA as an example of interdisciplinary working [A1]. King's research on CTOs (8), which were first implemented in the 2007 revision of the 1983 MHA, indicated that they were unlikely to improve key outcomes, including hospitalisations. This evidence informed the IRMHA's recommendation to put the CTO policy "*in the last chance saloon*" [A1 p28]. King's research underpinning this IRMHA recommendation has ensured that CTOs will continue to be scrutinised for their effectiveness.

Government committed to a new mental health legislation, a key component of which is King's recommendations on advance decision making. The Government responded to the IRMHA's final report on 6th Dec 2018, committing to bring forward new mental health legislation, and immediately accepting two of the IRMHA's recommendations based on King's research (1,2,3,5; published subsequent to IRMHA final report) [B1]. Both relate to advance planning: firstly that persons detained under the MHA would be able to nominate a person to make decisions about their care, to replace previous legislation that this role automatically fell to nearest relative; and secondly, that statutory ACDs would be introduced to allow patients, whilst in periods of mental capacity, to outline their preferences for care during periods of incapacity. The recommendation that ACDs should be used appeared in every stage of the parliamentary debate concerning the reform of the MHA [B2, B3, B4]. King's also conducted two "Policy Labs" during which ADM was discussed [B5, B6, B7] bringing the MHJ project members together with policy advisors from key Government departments and the NHS, alongside service users, representatives from various bodies involved in criminal justice, social work and charities, and other stakeholders.

King's researchers have worked proactively with policymakers to ensure the Government followed through on these recommendations. King's researchers effectively helped Government translate their research findings into law, building on earlier engagement with Government (Owen was a Parliamentary Office of Science and Technology research fellow on the

Impact case study (REF3)

Mental Capacity Act in 2011; Ruck Keene was a consultant at the Law Commission for the report on Mental Capacity and Deprivation of Liberty in 2017). This has involved King's organising an evidence session for parliamentarians and senior civil servants in the Westminster Parliament on 21st May 2019 [B8] chaired by the Rt Hon Baroness Margaret Jay, for which they provided a policy briefing document resulting from the Policy Labs on ADM [B9]. King's researchers have subsequently directly engaged with the civil servants responsible for drafting the White Paper in a series of meetings. A Senior Policy Advisor at the Department of Health and Social Care says: *"the advice was very helpful in informing our proposal on 'advance choice documents' in the White Paper"* [B10].

King's work on the IRMHA has provided a framework contributing to one of the goals of the NHS Long Term Plan. The NHS Long Term Plan states: *"It (the IRMHA) has examined rising detention rates, racial disparities in detention and concerns that the Act is out of step with a modern mental health system. The government is now considering the findings of the review in detail, including the need for better crisis services and improved community care for people with serious mental illness. Investment in these service forms a major part of this Long Term Plan"* [C p.69]. The recognition of ADM as being part of a modern mental health system forms a critical part of how the NHS can deliver on Government's commitment to give people more control over their mental health treatment [B6].

King's supported an early implementor of advance choice documents in the context of the Mental Health Act. Our work has led to the approval of the UK's first ACD clinic/workshop for service users at the South London and Maudsley NHS Foundation Trust, supported by the Trust's CEO David Bradley [D]. This initiative has allowed King's researchers to evaluate the success of early implementation, and to provide a model for other trusts in the future.

King's researchers inform Bipolar UK's strategy on providing advance choice documents. The charity Bipolar UK has been a committed partner with King's during our ACD work and subsequent advocacy for inclusion of ADM in MHA reform, and a survey of over 900 Bipolar UK subscribers found overwhelming support for ADM (7) [E1]. King's researcher Gergel drafted instructions and a proforma for making an ACD, which is now freely available on Bipolar UK's website so that visitors to the site can articulate their own advanced choices [E2, E3].

King's research informed the work of artist Beth Hopkins to raise public awareness about ADM. In 2019, service user artist Beth Hopkins was commissioned by the Bethlem Gallery to explore ADM for people with bipolar, and created work using King's research. COVID-19 has delayed a planned exhibition to examine notions of autonomy, which will be open to the general public [F1, F2].

Mental health charities, patients and carers welcome the ADM recommendations of the IRMHA. The Chief Executive of the leading UK mental health charity, Mind – which supports hundreds of thousands of people through its services, and up to 18,000,000 more a year through its website resources – recognises that the changes to the MHA informed by King's research are beneficial to the people that his charity supports. He said *"we are pleased to see that many of our concerns – and those of the people we represent and have supported to feed into the review – have been heard. The recommendations to strengthen people's rights, empower them to question decisions about their care, choose their treatment and involve friends and family have the potential to make a real difference to those who are in an extremely vulnerable situation"* [G1]. One carer bears witness to the impact on individuals: following a previous episode of psychosis in his partner during which inappropriate discharge arrangements had been made, an advance directive was drawn up. He says of a subsequent episode, *"we are extremely grateful that this document was adhered to when necessary during her hospital stay. This allowed us to continue communicating through her period of psychosis and to avoid a repeat of the damage to our relationship with the previous admission had caused"* [H1].

5. Sources to corroborate the impact

A Evidence to corroborate King's contribution to the IRMHA

A1 Modernising the Mental Health Act, Increasing choice, reducing compulsion. Final report of the Independent Review of Mental Health Act 1983, December 2018

Impact case study (REF3)

A2 Testimonial from Dr Thomas Kabir, McPin Foundation

A3 Testimonial from Professor Sir Mark Hedley, Co-chair of IRMHA

B Evidence to corroborate Government action taken as a result of King's research informing the IRMHA

B1 Government announcement of decision to adopt two recommendations of IRMHA immediately, another later, December 2018

B2 Queen's speech, 2019

B3 General debate on reform of the Mental Health Act 1983, 2019

B4 New Mental Health Act announced early 2021

B5 First Policy Lab details, 27th November 2017

B6 Second Policy Lab details, 16th February 2018

B7 Policy Lab report, Future of the Mental Health Act, 2018

B8 Evidence session at Westminster, 2018

B9 Policy Lab briefing for Margaret Jay, Advanced Decision Making, 2018

B10 Testimonial from a Senior Policy Adviser, Department of Health and Social Care

C NHS Long Term Plan**D Testimonial from David Bradley, Chief Executive Officer of South London and Maudsley NHS Foundation Trust****E Evidence supporting the partnership between King's researchers and Bipolar UK**

E1 Testimonial from the Chief Executive Officer of Bipolar UK

E2 Advanced choice documents on Bipolar UK website

E3 Dr Tania Gergel's documents sent to Bipolar UK from which they wrote the website page above

F Evidence supporting exhibition at The Bethlem Gallery

F1 Testimonial from Beth Hopkins, service user and artist

F2 Images from Beth Hopkins, service user and artist

G Evidence showing the impact on service users and carers

G1 Charity MIND's response to the Mental Health Act review, December 2018

G2 Testimonial from a carer.