Thalamos

UKRI Research England

King's College London

NHS South London and Maudsley NHS Foundation

Digital Advance Choice Documents

Deploying in a clinical setting

Version 5.0

Date April **2023**

Contents

Foreword 04

Milestones in ACD development 05

Executive summary 06

Project aim 07

Research so far 08

Why support ACDs? 08
ACDs are an ethical intervention 08
ACDs are an evidence-based intervention 08
Lived experience of ACDs 08
High demand, limited delivery 08
The need for a digital tool 10
Considerations for digital tools in mental health care 11
The clinical process of making an ACD 12
An evidence based, co-produced prototype digital ACD 13

Legal considerations 14

Overview 14
The legal frameworks 14
What should happen if a choice expressed in an ACD is not followed 14
Specific considerations for CTOs 15
Adverse outcomes where the choices expressed in an ACD are not followed 15
ACDs, self-completed advance choices and ADRTs 15
Conclusion 15

Stakeholders 16

Primary stakeholders 16
Secondary stakeholders 16

User types & authentication 18

Non-Professional users 18
NHS Professional users 18
Other Professional users 19

Digital MVP 20

Clinical Co-design 21
Structure 21
High-Level Requirements (User stories) 22

In scope MVP functionality 22
Out of scope MVP functionality 24

Interoperability requirements 26

For NHS Professional Users 26
For Non-professional Users 28
Data & insights 29
System-level view of ACDs 29

Deployment considerations 31

Information governance and data sharing 31
Clinical safety and actionable insights 31
Testing to embed user centred design 32
Stakeholder training 32
Benefits case 33

Discovery document summary 34

Glossary of terms 35

References 37

Appendix 39

Digital ACD MVP interface 39
Digital ACD MVP document 47

Foreword

Advance Choice Documents (ACDs) have been the most exciting part of reform of the Mental Health Act (MHA) but amongst the most difficult to get right.

I have seen huge progress on ACDs since the early discussions during the Government's Independent Review of the MHA in 2018. There has been wide consultation; new international evidence on the effectiveness of ACDs; innovative work with those with lived experience to co-produce practical tools and most importantly, work understanding the experiences of Black people (those most likely to be detained under the MHA). It is one of those welcome areas where a remarkable consensus exists to secure a way forward.

Previous progress with ACDs has been hampered by policymakers, commissioners, mental health practitioners and even patients themselves misunderstanding how best to develop and use ACDs to ensure they facilitate access; improve experience and provide better outcomes, and ultimately reduce the risk of compulsory detention.

Classic pitfalls include patients developing documents by themselves without input from their supporters and clinical team resulting in them being disappointed when their forms are not available at crucial times and when they are, their wishes not being adhered to.

Historically, ACDs have been paper-based, leaving them susceptible to unequal uptake, loss, and inaccessibility when most needed. Yet ACDs represent a real opportunity to make progress with properly developed, individualised plans that can be readily accessed, thus improving experience and outcomes for the most marginalised and disadvantaged at times of their greatest need.

I was delighted that at the start of 2023 the Joint Parliamentary committee on the Mental Health Bill urged the government to put ACDs on a statutory footing. Their recommendations will enable all people with experience of detention under the MHA to be supported to create an ACD and for it to be digitally accessible.

In this discovery document, we introduce a digitised ACD: the fruit of a research collaboration between King's College London and specialist mental health digitisation provider Thalamos. By shifting to a digital platform it becomes much easier to reach out to disadvantaged and underserved groups and also to provide a secure and readily updateable framework within complex care systems.

This digital ACD prototype is more than a digitised version of a paper document. It has been carefully designed to support users through what can be a complex and emotionally profound process of creating preferences for times of crisis using a person's own experience of their changing mental capacity over time. Furthermore, their creation can be integrated with electronic health records systems, ensuring communication of an individual's preferences to all those involved in mental health care provision at key points in decision-making. For too long service users have rightly asked why they should invest hope in creating ACDs when they cannot be properly read by the clinicians who need to enact their wishes and preferences.

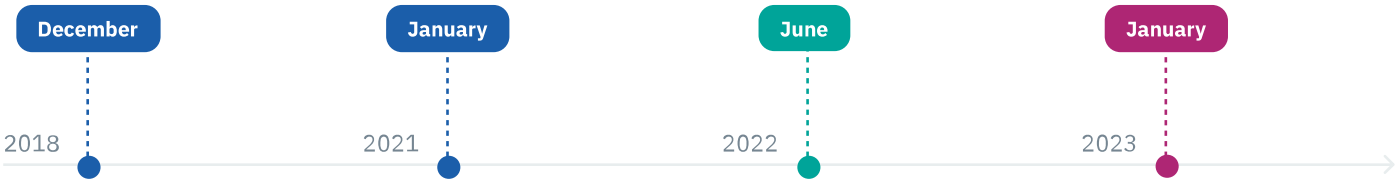
The discovery document lays out research background as well as legal, data privacy, safety and interoperability considerations. Importantly, it presents strategies to approach and manage them.

What I believe needs to happen now is accelerated problem-solving using implementation studies in NHS settings. Service users deserve choice and autonomy through realisation of ACDs and our NHS needs to gain experience and confidence in safe and effective ACD use.

I warmly invite you to explore this discovery document.

Dr Shubulade Smith CBE

Milestones in ACD development



Independent Review of the Mental Health Act (chaired by Professor Sir Simon Wessely)

Recommends ACDs are put on a statutory basis.

Government white paper on Reforming the Mental Health Act

Commits to introducing statutory ACDs to enable people to express their view on the care and treatment that works for them as inpatients, before the need arises for them to go into hospital.

Draft mental health bill

Estimates costs and benefits for ACDs without a statutory role

Report of the Joint Committee on the Draft Mental Health Bill – House of Commons and House of Lords.

Recommends that government strengthen its proposal on advanced choice and give patients a statutory right to request an ACD setting out their preferences for future care and treatment, thereby strengthening both patient choice and their voice. Patients should have support in doing do. Specifies that ACDs should be recorded in a way that is accessible digitally.

Executive summary

Advance Choice Documents (ACDs) enable people who need to use mental health services to record their advance preferences for treatment and care they may need during mental health crises and hospital admissions.

In 2022, the government published its Draft Mental Health Bill. In January 2023, the Joint Committee, chaired by Baroness Buscombe, published its report on the draft Bill, recommending that it must be strengthened to address rising numbers of people detained under current legislation and tackle unacceptable and inexcusable failures on racial inequalities. The report gave a specific recommendation on ACDs:[33]

> *"We recommend that there should be a statutory right for patients who have been detained under the Mental Health Act to request an advance choice document be drawn up. These should also be offered to everyone who has previously been detained, as recommended by the Independent Review." (p. 82)*

> *"[ACDs] should be recorded in a way that is accessible digitally" (p. 82)*

This document summarises the findings of a Research England-funded policy support project between King's College London and Thalamos Limited exploring the feasibility and value to stakeholders of a digital version of an ACD to deliver this intervention at scale.

The intervention reflects over twenty years of integrative research experience on ACDs based at King's College London/SLaM. The digitalised ACD is based on a template jointly developed by the AdStAC programme which has been exploring advance statements for Black African and Caribbean people and the Mental Health and Justice Project. The research underpinning the digitisation process is discussed in more detail in 'Research so far'.

This document focuses on how ACDs may be delivered in a digital format to deliver an ethically and empirically based intervention at scale for people across health and care settings. This document is accompanied by a Digital ACD Minimum Viable Product (MVP) for use in further implementation studies. An MVP is an early version of a product with just enough features to be usable, which are useful tools for validating product assumptions and gathering feedback. The feasibility and value to deliver all high-level requirements to all stakeholders via a large scale roll out are discussed throughout this document including integrations with other systems and wider pieces of work for consideration before deployment. The Digital ACD MVP can be accessed via the project board leads, Dr Gareth Owen and Dr Lucy Stephenson and a PDF version is included in this document.

The project has been led by Dr Gareth Owen and Dr Lucy Stephenson. The project team is comprised of following people:

- **Dr Gareth Owen** - Reader in Mental Health, Ethics and Law at KCL and honorary consultant psychiatrist at the South London and Maudsley NHS Foundation Trust. Co-Investigator on the AdStAC project, Principal Investigator of the Mental Health and Justice Project.

- **Dr Lucy Stephenson** - Speciality Trainee in Psychiatry and Medical Psychotherapy at South London and Maudsley NHS Foundation Trust, Clinical Research Associate King's College London. Completed PhD focussed on co-producing and piloting a prototype ACD.

- **Dr Shubulade Smith CBE** - Visiting Senior Lecturer in the Department of Forensic and Neurodevelopmental

Sciences at the IoPPN and a Consultant Psychiatrist at the South London and Maudsley NHS Foundation Trust. President Elect of the Royal College of Psychiatrists. Principal Investigator on the AdStAC project.

- **Professor Claire Henderson** - Honorary Consultant Psychiatrist, South London and Maudsley NHS Foundation Trust; Senior Personal Tutor, GKT School of Medicine; Academic Lead for the Quality Centre, King's Health Partners; Director of the Centre for Implementation Science, King's College London. Co-Principal Investigator on the AdStAC project.

- **Alex Ruck Keene KC (Hon)** - Visiting Professor at the Dickson Poon School of Law, KCL. Barrister, writer, academic and educator. His practice is focused on mental capacity, mental health and healthcare law. Research Fellow on the Mental Health and Justice Project and consultant on the AdStAC project.

- **Thalamos Limited** - a digital health business specialising in system level software focused on mental health law, in particular the Mental Health Act (MHA) and the complex MHA pathways across organisations. From Thalamos, the following people have worked on this project:

- **Mackensie Dyer** - Product Manager
- **Rachel Tesfaye** - Senior Programme Lead
- **Stuart Smith** - Software Engineer
- **Arden Tomison** - CEO
- **Ross Tomison** - COO
- **David Williams** - Interim CTO
- **Dr Iain Grant** - Clinical Safety Officer and Governance Advisor
- **Steve Gilbert** - Living Experience Consultant and Governance Advisor. Steve is also an advisor to the AdStAC project
- **Dr Debbie Martin** - AMHP, Educator and Governance Advisor
- **Phil Walker** - Data Protection Officer and Governance Advisor

Project Aim

This project brings together existing academic research into advance choice interventions with the learnings of a specialist eMHA software supplier to serve as a guide for implementation of digital ACDs. It does so by outlining the key areas that must be considered and offers actionable insights to deployment approaches and interoperating with the relevant clinical and non-clinical systems. A digital ACD MVP has been co-developed for use in further implementation studies which will validate the findings of this document.

Research so far

Why support ACDs?

Reasons to support ACDs fall into two main groups: firstly conceptual reasons (i.e. ethical arguments) and secondly empirical reasons (i.e. evidence demonstrating the advantages of introducing ACDs into mental health care).

ACDs are an ethical intervention

The key ethical arguments for ACD stem from the potential they hold to promote the autonomy of someone living with mental illness[1], improve well-being and enhance therapeutic alliance.[3,4] Human rights organisations have understood ACDs (and their equivalents) to be an important tool in rebalancing some of the inequalities that people living with disabilities face. [2]

ACDs are an evidence-based intervention

Empirical research on ACDs has so far established the following:

- People living with severe mental illness consistently say they would like to make ACD. Surveys in the US and UK concur that the majority (74%-88%) of respondents would like to make ACDs.[3, 5]

- ACDs can reduce the amount of involuntary treatment a person living with severe mental illness receives.

  Several RCTs evaluating the outcome of interventions to create documents which functioned as ACDs (with names such as Joint Crisis Plans and Psychiatric Advance Directives) have assessed the impact of these documents on involuntary hospital admissions. [6, 10] Although results of individual trials varied meta-analyses suggest that overall there is a significant reduction in compulsory admissions.[11, 12]

- ACDs can improve therapeutic alliance.

  A multi-site RCT of ACDs in the UK established that this is an intervention that can significantly improve therapeutic alliance.[6, 13] Qualitative research revealed that this may be because the process of making the document offered a way of communicating and care planning that felt more empowering and offered 'consistent respect' for the Service user.[14]

- ACDs are likely to be most cost effective when used by Service users from Black communities.

  It is well established that Service users from Black communities have disproportionately high rates of detention.[15] The Independent Review of the Mental Health Act [16] set out to address this as a key aim. It is of note that in a multi-centre UK trial of an ACD equivalent (Joint Crisis Plans) it was shown that ACDs had the highest cost effectiveness for services when used with Black Service users.[17]

Lived experience of ACDs

The following quotes are taken from Service users, their friends/family members and professionals who were involved in the pilot project of a prototype ACD conducted by the KCL research team: High demand, limited delivery

High demand, limited delivery

There are clear ethical reasons and an evidence base in support of using ACDs in healthcare. However, research also suggests that implementation has been consistently challenging in multiple international settings.[3,4] Most notably, in Scotland where there is statutory support for 'Advance Statements,' uptake has only been 6.6% amongst people who have been involuntarily admitted to hospital.[18]

"It makes me feel a little bit more in control…if I'm going to go into a crisis, that I've got that sort of as a plan."

It makes it a little bit less scary because hopefully my views will be the priority within services if I need support, in A&E or whatever it may be, in the future."

Service users talking about the importance of their ACDs to them

"Not only will it beneficiate [the Service user] but it will also beneficiate [the Service user's] environment, like [the Service user's] family and I, what we will be aware what to do, what are the next steps that we need to follow, and what is the best way. And not only what to do, but as well what not to do."

A family member talking about the importance of making an ACD to them

"[The Service user] had to go to a private hospital on this admission… And as part of the process of transferring notes over, obviously a risk assessment and care plans, but also I could pass on that [ACD] as well, and it's a really good summary of what [the Service user] wants and cares about."

A care coordinator reflecting on how the ACD helped facilitate communication between services during a crisis admission

- **Barriers to implementation**

  A 2014 review of barriers around implementing ACDs concluded that there were barriers at a system level (legal liability, provision to override, resource constraint), health professional level (lack of knowledge, fear of treatment refusals, concerns about impact on clinical care, reluctance to facilitate, Service user capacity) and Service user level (lack of trust, support, knowledge, understanding and concerns about health professional attitude and revocability).[19] In a large UK wide RCT evaluating a form of ACD (the Joint Crisis Plan), it was suggested that the most important barrier to address may be clinician engagement.[20]

- **The importance of the facilitator role**

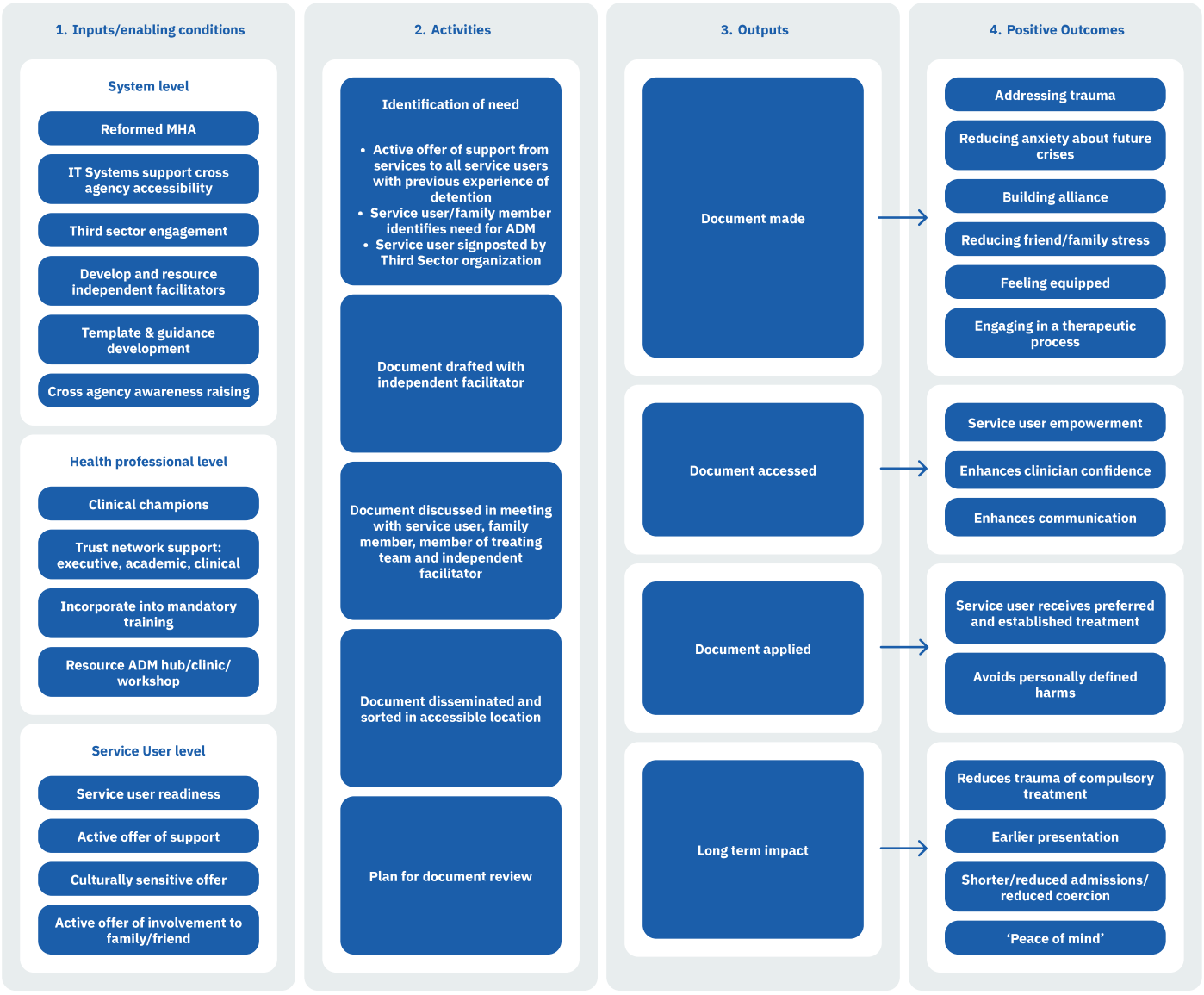
  Studies in the US, Europe and UK have consistently demonstrated the importance of a facilitator in implementing ACD-type documents. The involvement of a facilitator has been shown to significantly increase uptake[13] and improve the therapeutic alliance.[14] Models have been trialled in which facilitators have backgrounds in advocacy, social work and lived experience or psychiatric nurses.[23] These documents achieved similar results on their impact on admissions but documents facilitated by those with an advocacy focus were found to be of higher quality.[24] The success of ACDs facilitated by peer workers was confirmed in a recent French RCT.[25]

"[Facilitator] input has been invaluable, because it's made it accessible.... A lot of the time we can't be arsed, because we're downtrodden and repeat ourselves so many times"

A Service user talking about the importance of a facilitator in the process has captured the position this way

- **Enabling factors for implementation**

The logic model below summarises enabling factors for ACDs based on results from a stakeholder focus group and consultation[21], a pilot ACD implementation study which included qualitative interviews with stakeholders[22] and the expert consensus of the current discovery document's authors:



The need for a digital tool

- **Learning from previous research**

Previous research on ACDs in the US identified a digital solution as a tool to address the issue around lack of clinician support to make documents. Researchers designed a computer programme which provided educational materials and video clips then directed users to create an ACD. The team found that 65% of a sample of 60 people

with severe mental illness were able to use the programme to complete a document. Feedback from the Service users suggested one of the most important components was having a structured approach to creating a document rather than blank space. Groups that found using the programme more difficult were those with lower educational status, with a learning disability and those from minority groups.[26]

- **Learning from physical health care**

  Within physical health care ACD equivalents are comparatively well established. A notable example in London was 'Coordinate my Care' (CmC). This was developed in the field of palliative care as an online service which supports the creation and storage of details about people's advance choices for preferred treatment, care and place of death. This was successfully used by Service users and their supporting health professionals to create over 144,000 advance care plans.[27] A forthcoming study of the use of CmC by people with a primary diagnosis of severe mental illness showed that this service was used by or on behalf of over 1800 people.[28] Also of note is the opportunity that services such as CmC offer to collect data which can be used to understand the uptake of ACDs and improve them. A second notable example that has been widely adopted outside London is the ReSPECT process. ReSPECT is supported by the UK Resuscitation Council and aims to enable high quality discussion of Service user preferences and clinical recommendations for emergency physical health treatment and care to record on a structured template document.

- **Learning from the pandemic**

  During the pandemic there was increased reliance on digital tools to deliver care. The Mental Health and Justice ACD pilot (the Crisis PACk project) worked with people diagnosed with bipolar and experience of detention. It was conducted almost entirely online.[22] This provides further weight to the argument that it is feasible to work with digital tools with this population.

- **Addressing accessibility issues**

  A persistent concern about implementing ACDs is their accessibility in a crisis.[21]

> *"I'm glad to have it there. I just hope that it gets looked at"*
>
> Service user

> *"Nobody knows where to find it, they don't look for it anyway."*
>
> Service user

A digital tool offers the opportunity to address this in a number of ways. Digital allows the format and accessibility of documents to be standardised at a system level. The potential to integrate with other digital systems clinicians are already using can also facilitate ACD creation by leveraging existing workflows and systems. Integration with other systems is also the only feasible way of making an ACD accessible at point of crisis or during a Mental Health Act admission by surfacing the ACD in systems which the professionals involved in care and treatment already have access to.

Considerations for digital tools in mental health care

We have outlined the clear advantages to a digital tool supporting ACDs. However, there are digital implementation

issues to be addressed which are outlined below:

- **Authentication**

  'Authenticating' is about ensuring appropriate security around who can sign into and use a digital system. ACDs will contain highly sensitive personal data and the need for ease of access to this data by professionals will need to be balanced with the need to protect people's data. There will need to be clarity around stakeholders in the process and the system supporting the digital ACD will need to have appropriate protections around who can sign into to edit and view documents.

- **Access**

  Multiple digital systems are used within healthcare systems across England and Wales. The digital ACD must hold the potential to integrate with those systems which are most relevant for its use to ensure accessibility when clinically required.

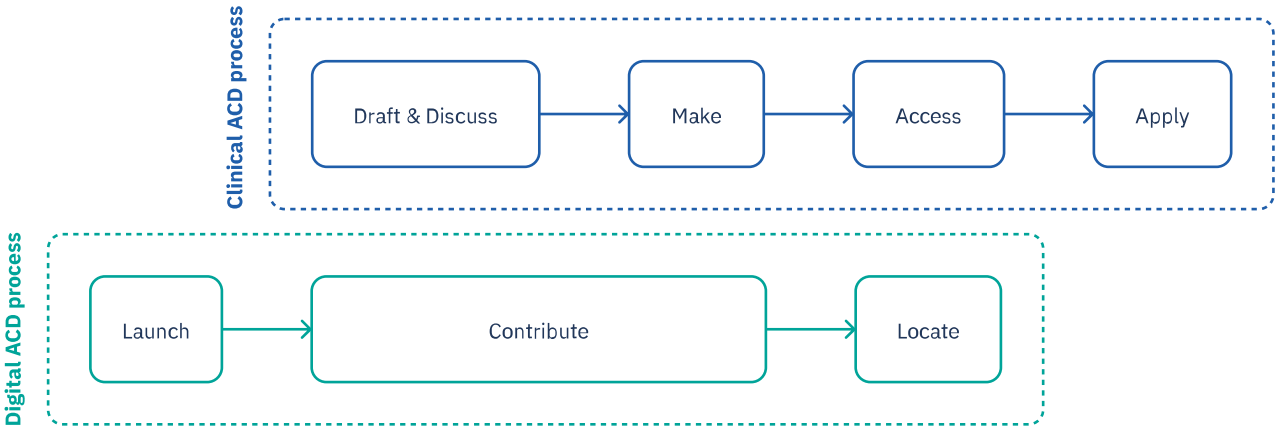
- **Digital inequalities**

  Many people who may benefit most from creating an ACD may not have access to a desktop computer or the internet. They may not feel comfortable using a digital interface. The digital ACD and model for its use must be flexible enough to cater for this group and avoid digital exclusion.

The following section outlines the prototype ACD produced during a collaboration with researchers from King's College London and Thalamos and describes the approach to addressing these challenges.

The clinical process of making an ACD

This figure shows the basic digital process overlaid on the clinical process for making an ACD prototype:



To make an ACD, the Service user can draft their preferences for care with an independent facilitator (see Primary Stakeholders). Then a meeting is held with the Service user, family or friends, a facilitator and health professional to discuss their preferences and formulate a plan. Finally, the document is disseminated to maximise the success of future access attempts in a crisis.

The document needs to be accessible at the clinical point of need. This is likely to be in a mental health crisis when use of the Mental Capacity Act or Mental Health Act is being considered e.g., accessible to an AMHP and section 12 doctors to inform a Mental Health Act assessment and accessible to the ward Consultant in drawing up a care and treatment plan. Once accessed, the document needs to be applied by clinicians at the point of clinical need (i.e., decisions need to be made on how the document contents inform treatment and care).

The digital process of making an ACD requires additional steps and considerations. The document must be launched

within the digital system, it needs to be contributed to by various parties and it needs to be located within the digital system at the point of clinical need. This Digital ACD is explored throughout this document.

An evidence based, co-produced prototype digital ACD

Researchers at King's College London have been working on models of advance decision making for over two decades. Dr Claire Henderson conducted the first randomised control trial of 'the joint crisis plan' in SLaM services[7], which was taken forward in a major multi-centre UK trial.[6] This model of collaborative care planning involving a facilitator has been replicated in international trials.[8,25]

More recently Dr Gareth Owen, Dr Lucy Stephenson and Alex Ruck Keene have been involved in work on mental health advance decision making as part of Mental Health Act reforms.[1] As part of this work an advance decision making template (called the PACT template) was co-produced in stakeholder focus groups[21] then developed in a pilot implementation study[22]. The final output was a document called the 'Crisis PACk' which responded to issues that arose during the pilot study as suggested by study participants (Service users, health professionals and carers).

Concurrently in SLaM a clinical service called 'Crisis Plus' was developed in one borough to respond to winter service pressures that were increased by repeat presentations to A&E. This team was led by a psychologist and involved engaging with services and Service users to formulate feasible crisis plan documents.

The Crisis PACk and Crisis Plus model have been further evaluated and developed by a newly formed research group called AdStAC. This work has focused on implementing these models of advance decision making with people living with SMI who are from Black communities and at the highest risk of detention under the MHA.

From all the work done so far it has become clear that a template and process for completion that is compatible with digital systems is urgently required for implementation. Therefore, a research team collaboration comprised of Prof Claire Henderson, Dr Lade Smith, Dr Gareth Owen, Dr Lucy Stephenson and Alex Ruck Keene formed to optimise the available models and template to create a digital version with the Thalamos team.

Thalamos was founded in 2018 as a for-profit, for-purpose business with the aim of improving outcomes in mental healthcare for Service users and clinicians. Thalamos has been heavily influenced by the recommendations of the Wessely Review, which was also published in 2018 and highlighted the need for ACDs in the MHA. The Thalamos flagship eMHA software allows all stakeholders involved in care to complete their statutory MHA function and communicate across the organisations involved in care. Thalamos was named as preferred supplier for the Pan-London MHA Digitisation Programme in 2022. This programme will place software in the hands of all mental health professionals across London at the point of assessing a Service user. If an ACD were to exist, this platform offers a digital option of surfacing an ACD at the exact point a person is assessed under the MHA providing a very practical opportunity to offer less restrictive methods to removing the person's liberty at point of assessment.

Legal considerations

Overview

ACDs are not legally binding documents, but they contain information which should be taken into account by professionals treating the person in a crisis. In some cases, they may contain an advance decision to refuse treatment which may require specific consideration by such professionals.

Given the emphasis within the Codes of Practice to the Mental Health Act 1983 ('MHA') and Mental Capacity Act 2005 ('MCA') upon respecting the current and previous wishes of Service users, having systems in place within organisations to support the making of ACDs and access to them in crisis is therefore important to support defensible decision-making by the treating professionals involved.

The legal frameworks

If an adult* is admitted informally, then if they currently have capacity to make decisions about their care and treatment, the basis for treatment must be their capacitous consent. If the person currently has capacity, treatment cannot be administered if the person does not agree to it. If the person currently lacks capacity to make decisions about their care and treatment, the provisions of the MCA allow for treatment to be provided if the professionals involved reasonably believe that is in the person's interests. At that point, the professional must take into account any advance statement made by the person as to what they would wish or not wish. If the person has made an advance decision to refuse treatment (ADRT) then, if it is valid and applicable, that treatment cannot be provided.

If a person is admitted under the MHA, then their treatment for mental disorder is subject to a number of safeguards. The Code of Practice to the MHA makes clear** both that people should be supported to express choices in advance about such treatment, and that professionals should seek to take into account such choices.

If the person has made an advance decision to refuse ECT it is binding unless the specific circumstances provided for in the MHA arise. If a person has made an ADRT for mental disorder, then such treatment cannot be provided whilst they are in the community subject to a Community Treatment Order. Otherwise ADRTs are non-binding.

What should happen if a choice expressed in an ACD is not followed

Although there is no formal statutory obligation to follow a choice expressed in an ACD under all circumstances, the Code of Practice to the MHA makes clear (at paragraph 9.17) that professionals should make all practicable efforts to comply with these preferences and explain to Service users why their preferences have not been followed.

It is important to note that it is not possible to require a medical professional to provide treatment which the professional does not consider clinically appropriate. It is entirely acceptable for a person to indicate that they would wish to receive treatments which others might regard as unconventional, but they cannot therefore bind treating professionals in a crisis to provide them with that treatment.

A person may well also make clear in an ACD that they would wish to be admitted at an early stage in an evolving crisis in order to secure against the risk of further deterioration. Those involved in admission can and should take that wish into account, but it does not affect their duties to assess them (if formal admission is being considered) by reference to the criteria contained in the MHA 1983. That may mean that the person is not admitted at the point at which they would have wished.

Finally, a person may make clear in an ACD that their desire to remain in the community is such that they are content for home treatment teams or their equivalent to take robust steps to support them. Such indications may well give home

*Different considerations may apply in relation to those under 18, which are not covered in this discovery document.
**See paragraphs 1.9, 9.4 and 9.17 in particular.

treatment teams confidence to be assertive, even if they cannot override the rule that treatment in the community can only be administered on the basis of capacitous consent or (where the person lacks capacity to consent) on the basis of a reasonable belief that the actions are in the person's best interests.

Specific considerations for CTOs

ACDs can be used for those on CTOs as well as those currently detained in hospital.

Adverse outcomes where the choices expressed in an ACD are followed

An important aspect of the ACD process is that it makes it easier to record contemporaneous evidence of capacity in relation to key matters, rather than having to rely after the event on retrospective reconstruction/normal practice so potentially reducing liability for clinicians involved in the drawing up of the ACD.

Conversely, there may be grounds for the actions of the treating clinician at the time to be questioned if an adverse outcome occurs when the choices in an ACD are not followed (especially choices which have been endorsed by the clinician involved in drawing it up) and there is no documented rationale for deviation from the person's choices as recorded in the ACD.

ACDs, self-completed advance choices and ADRTs

The ACD model that this discovery document accompanies anticipates a facilitated process between the person and clinical team. It is based upon the premise that such a process is likely to be the most effective in terms of ensuring appropriate weight is placed upon the person's choices at the point of crisis or during a hospital admission. However, some people may wish to create their own document without any clinical involvement. Issues arising at that point, the interrelationship between any such document and any document created under this model, and confidence levels as to the identity and capacity of the person creating the document. Some of these issues are examined in the 'Interoperability' chapter below.

The Digital ACD that this Discovery document accompanies does not provide for the making by those subject to the MHA 1983 of advance decisions to refuse physical health treatment. A further discovery document is likely to be necessary to cover this situation. In the meantime, someone who wants to make one of these should be supported to complete one, and the ACD make clear where the document is to be found.

Conclusion

ACDs can in theory contain all the various statements of wishes provided for above. They therefore enable both the Service user in advance and the professionals at the point of crisis to navigate the provisions of sometimes complex and overlapping legal frameworks. It is therefore important that systems are developed to enable their effective creation, recording, and access in crisis.

In the following sections we discuss the approach we took to addressing key challenges in creating a digital MVP ACD: Defining stakeholders, system user types and authentication, and access issues.

Stakeholders

Primary Stakeholders

The Primary Stakeholders are the direct users of a digital ACD application. These people need to participate in document creation and management in order to fulfil the purpose of the ACD. Within the scope of this study, this includes the Service user, Facilitator and Clinician, who together are responsible for collaboratively producing an ACD. The Digital ACD MVP facilitates input from Primary Stakeholders only.

Stakeholder	Description	Objectives	Organisation
Service user	A person who has previously been detained under MHA for whose benefit the ACD is intended. Ultimately, the Service user is the decision-maker in the creation of the ACD.	• Service user autonomy and choice • Therapeutic benefit • Reduce the need for compulsory treatment and/ or improved the experience of compulsory treatment.	N/A
Facilitator	An independent contributor who has been onboarded by the relevant service provider to coordinate the completion of ACDs with Service users and wider clinical teams. The facilitator health professional, advocate, peer supporter or other third party who has received specific training.	• Ensure that the ACD accurately reflects the Service user's voice. • Ensure the Service user has the means to create an ACD, including supporting access to digital tools (e.g. computer, internet access) • Ensure that the clinical team is engaged where possible. • Ensure the ACD is digitised and disseminated correctly.	NHS Trust
Clinician	A GP, psychiatrist or other appropriate health professional who has specific roles in the creation of the ACD. The clinician will usually belong to the NHS organisation to which the Service user is registered.	• Contribute their recommendations for crisis mental health treatment and care based on the facilitated discussion with the Service user. • Provide information on mental capacity to make decisions about treatment and care at the time the document is drafted • Able to easily access a completed ACD at the point of clinical need. • Clearly understand the Service user's preferences for treatment/care.	NHS Trust

Secondary stakeholders

Secondary stakeholders are the indirect users of digital ACDs who would be crucial to wider implementation, promotion and support if ACDs were to be used operationally. This section identifies the needs of secondary stakeholders that must be addressed if deploying digital ACDs in a clinical setting. The Digital ACD produced alongside this report does not support input from secondary stakeholders. The extent to which these stakeholders will be users of a digital ACD application will depend on the value added and the economics of a wider operational roll out.

Stakeholder	Description	Objectives	Organisation
ACD Champions	Individuals appointed to collate expertise and facilitate intra- and inter- agency learning in organisations involved in responding to mental health crises.	• Support roll out of high quality ACDs • Develop education and training tools • Awareness raising around ACDs • Local data collection, audit and evaluation of ACD use • Trouble shooting in ACD implementation	Mental health Trust
Approved Mental Health Professionals (AMHPs) / Social workers	AMHPs/social workers are approved by local authorities to carry out specific duties under the Mental Health Act, such as coordinating assessments and hospital admissions for sectioned individuals	• Able to access ACD at key points of medico-legal decision making (e.g. Mental Health Act Assessment) to inform assessors about a person's wishes	Local Authority
Carers/supporters	Supporters of the person that the ACD is being created for. This group could include friends and family.	• Peace of mind that their loved ones will receive appropriate care • Clarity on their role in supporting their family member in crisis.	N/A
CQC	A government agency that is responsible for independently regulating health and social care in England, ensuring standards of safety for Service users.	• Further data on which to base Second Opinion decisions. • Further monitoring data on the use of ACDs across organisations	Department of Health and Social Care
Independent Mental Health Advocacy (IMHA)	An independent advocate who is trained in the MHA and supports people to understand their rights under the Act and participate in decisions about their care and treatment.	• Being the voice of the Service user • Supporting Service users to understand their rights	Local authorities/Third sector organisations
Police services	Police officers responding to mental health call outs. This stakeholder is likely to encounter people at the point of crisis and making an ACD readily available could improve Service user experience.	• Reduce the level of Police involvement in acute crisis admissions • Provide clarity for officers as to the right course of action for the person being detained	Police
Third Sector Bodies	Enabling bodies that advocate the use of ACDs and support Service users in recovery from crisis.	• Provide properly resourced less restrictive interventions. (e.g. Crisis Cafés). • Ensure Service user rights are upheld.	Voluntary
Tribunal members	Mental health tribunal, including Chair (lawyer), a medical member and a lay member	• Able to access ACD to inform mental health tribunal decision making	Ministry of Justice
Trust IT teams	An IT team responsible for managing the deployment of digital ACDs in organisational settings.	• A tool which is easy to implement, integrate with other systems and which has low user support requirements.	NHS Trust
Ward teams	Skilled medical team responsible for in-Service user hospital care.	• Aware of ACD at point of care as an in-Service user • Able to access ACDs to inform statutory Care and Treatment plans	NHS Trust

User types & Authentication

A complete digital ACD must be able to fulfil the objectives of the Primary and Secondary stakeholders. In the context of a digital system, defining Primary and Secondary stakeholders as user types contributes to meaningful discussion around software considerations for roles, privileges, and authentication at the organisation and system level. This section outlines three core user types and the considerations for them to access a digital ACD system.

User type	Description	Potential stakeholders included
Non-Professional users	Service users and any of their friends, families or representatives who need access to the ACD either whilst it is being prepared or once it is complete.	• Service user • Carers/supporters
NHS Professional users	Mental health professionals belonging to an NHS organisation who will need access to a digital system as part of their professional role. This includes all mental health professionals involved in preparing the Digital ACD and those who may need to access the Digital ACD once it has been completed.	• Facilitators • Clinicians
Other Professional users	Other users who are not 1) Mental health professionals and/or 2) belonging to an NHS organisation. This includes other healthcare, local authority and state organisation staff who may be directly or indirectly involved with digital ACD implementation as part of their professional role. There may not always be a need for this group to access ACDs but signposting their existence should be considered.	• AMHPs • Social workers • Trust IT managers • Charities • CQC • Police services • Private health providers • Tribunal members • Ambulance service

Non-professional users

These users are unlikely to have access to existing clinical systems, so the approach to digital Service user engagement across local and national policy should be considered to provide an appropriate point of digital access for Service users to ensure a sense of ownership for an ACD co-authored with a facilitator. For inclusivity, there will need to be digital and non-digital methods for non-professional user access to ACDs (explored further in Deployment Considerations). The scope of this project includes authentication to a Digital ACD MVP for the Service user during the completion of the digital ACD and the ability to retain their ACD in PDF format.

Research so far suggests that these users are more likely to have access to mobile devices rather than large screen formats (e.g. tablets, laptops and desktops). They may have email access in some way, but other messaging services such as WhatsApp may be more widely used. Additional work is required as part of an implementation study to understand the long-term operational requirements for non-professional access to a digital ACD, or the system hosting it. The needs of all friends, families and other representatives should be considered as part of a wider implementation study as to the need to access a digital ACD, when this may be appropriate and what methods this might be facilitated by.

NHS Professional users

NHS professional users who belong to the same organisation (i.e. an NHS Trust) will have access to the digital systems authorised for use within that Trust IT system. For example, NHS professional users within SLaM Trust are authorised to use ePJS. NHS professional users outside of SLaM may not be authorised to access ePJS.

It is important that NHS professional users authenticate within a digital system of some kind to preserve audit trails and permission levels. Moreover, non-professional users who are participating in the creation of an ACD will usually be

registered to the same Trust as the NHS professional users. It would therefore be feasible to implement digital ACDs within a Trust, as authentication could be managed within a single IT system.

However, to promote the goal of a single, unified digital system, NHS professional users working for different NHS organisations will need to access a digital ACD service if a Service user presents to them. Inter-organisation working is essential to remove the potential barrier of a lack of clinical engagement with ACDs which in turn would undermine Service user choice.[20] It is essential to consider how all NHS professional users will be able to access digital ACDs for a Service user regardless of the Trust they belong to. This points to the advantage of a system-level approach to ACD implementation over Trust-level.

The scope of this project only includes users who need to authenticate within the digital ACD MVP and does not include authenticating within third party systems. The opportunities to integrate with other systems are discussed in Interoperability Requirements and should be explored as part of an implementation study.

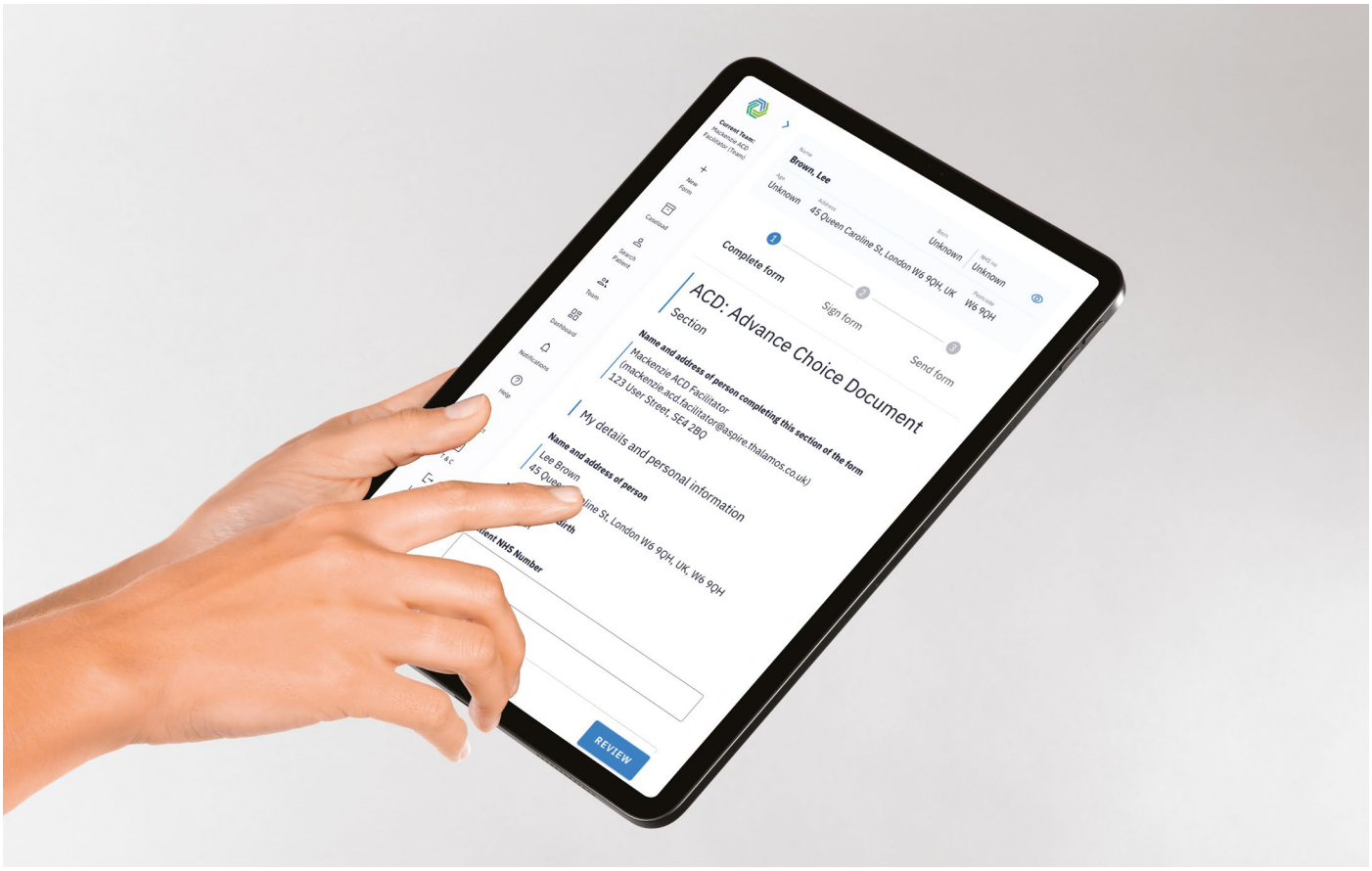
Other Professional users

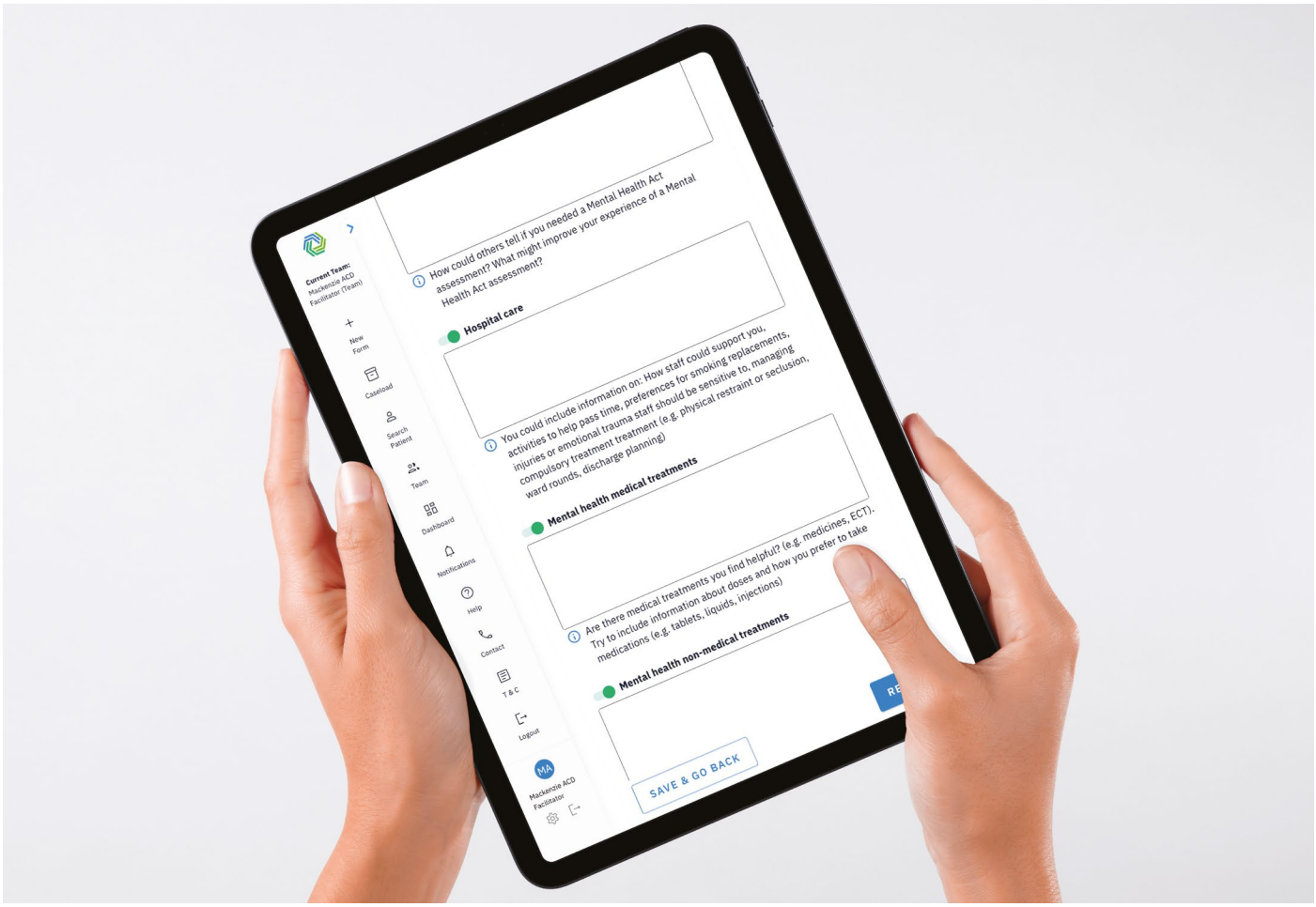
Beyond the scope of this project, there is another type of professional user who may require access to a digital system in some way. This group of users may not belong to an NHS organisation, but – for role, audit and security purposes – it is still important to consider how they could authenticate and access digital ACDs to fulfil their respective needs. Some examples may include:

- Mental health professionals belonging to other healthcare organisations, such as AMHPs or social workers operating on behalf of local authorities.
- Police services responding to mental health calls where there is a need to access or be made aware an ACD is in place at the point of crisis.
- Governing bodies, such as the CQC, monitoring digital ACD uptake across different NHS organisations

Again, a system level approach to ACD implementation is likely necessary to ensure professional users belonging to different organisations can authenticate to either the same digital system, or another system which knows an ACD exists via integrations.

Digital MVP


Brown, Lee
Unknown
45 Queen Caroline St, London W6 9QH, UK
Unknown
W6 9QH
Complete form
Sign form
Send form
ACD: Advance Choice Document
Section
Name and address of person completing this section of the form
Mackenzie ACD Facilitator
(mackenzie.acd.facilitator@aspire.thalamos.co.uk)
123 User Street, SE4 2BQ
My details and personal information
Name and address of person
Lee Brown
45 Queen St, London W6 9QH, UK, W6 9QH
REVIEW


How could others tell if you needed a Mental Health Act assessment? What might improve your experience of a Mental Health Act assessment?
Hospital care
You could include information on: How staff could support you, activities to help pass time, preferences for smoking replacements, injuries or emotional trauma staff should be sensitive to, managing compulsory treatment treatment (e.g. physical restraint or seclusion, ward rounds, discharge planning)
Mental health medical treatments
Are there medical treatments you find helpful? (e.g. medicines, ECT). Try to include information about doses and how you prefer to take medications (e.g. tablets, liquids, injections)
Mental health non-medical treatments
SAVE & GO BACK

Clinical Co-design

The digital ACD MVP is a reactive web-application hosted on the Thalamos infrastructure. It is the output of an initial co-design process between KCL/SLaM research teams and Thalamos. Learnings from the research so far and, in particular, from the Crisis Pack and AdStAC projects (which focus on understanding Service user experience), have been incorporated into the MVP to promote lived experience and clinical safety by design.

The purpose of the MVP is to help to inform an approach to wider implementation of digital ACDs. The Deployment Considerations and Interoperability Requirements sections of this document outline the work required to operationalise this to be a practical tool that addresses the needs of professional and non-professional users beyond an early implementation project. The Digital MVP provides functionality for the Primary Users described in the Stakeholders section.

Structure

The digital MVP is made up of 7 sequential parts that contain individual sections. Each part can be completed by the respective user, supporting collaborative input from the different stakeholders involved in ACD creation.

ACD part	ACD section name	Completed by
1	• My details / personal information • Who I am • Health difficulties • Care in crisis (Appendix example 1A & 1B) • My preferences for treatment and care • Practical help • Key crisis supporters • How people can access this ACD	• Service user • Facilitator
2	• Mental health treatment and care recommendations (Appendix example 2A & 2B)	• Facilitator
3	• Mental capacity (Appendix example 3A & 3B)	• Clinician
4	• Other views	• Facilitator
5	• Clinician signature	• Clinician
6	• Service user signature (Appendix example 4A & 4B)	• Service user • Facilitator
7	• Facilitator signature	• Facilitator

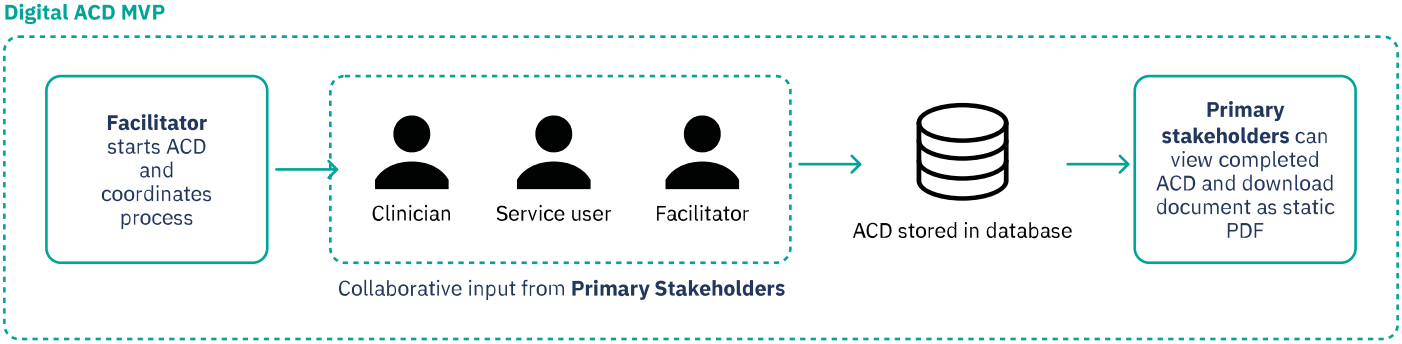
High-Level Requirements (User stories)

A 'User story' gives a short, simple description of a goal from the perspective of the user and provides a way to meaningfully articulate how a software feature could provide value. This table considers the features a complete digital ACD system would need to enable and identifies those that have been included within the MVP scope. These User Stories can be considered the High-Level requirements of a digital ACD system.

Ref.	Digital feature	User story	User types involved	MVP feature
1	Requesting a new ACD to be created	As a Service user, I want to request an ACD to be created, so that I can state my preferences for treatment and care in the event of a crisis.	• Non-professional user	No
2	Launching a new ACD	As a Facilitator, I want to start an ACD, so that I can support the Service user involved and coordinate therapeutic alliance between the Service user and other clinicians.	• Non-professional user • NHS professional user	Yes
3	Contributing to an existing ACD	As a Service user, I want to collaborate with a Facilitator and other Clinicians, so that I have ownership over the creation of my care and treatment preferences.	• Non-professional user • NHS professional user	Yes
4	Accessing an ACD at the point of clinical decision making	As a Clinician responding to a Service user in crisis, I want to know that an ACD exists and be able to access it easily, so that I can promote ethical and evidence-based intervention.	• Non-professional user • NHS professional user • Other professional user	Yes
5	Requesting updates to an ACD	As a Service user, I want to be able to access my own ACD and update my ACD if my circumstances change, so that I have a sense of control and it is always up to date with my preferences.	• Non-professional user	No
6	Locating an ACD to review or update	As a Facilitator, I want to know when an ACD is due to be reviewed, so that I can advocate a Service user's choice to make changes to their ACD.	• NHS professional user	No
7	Locating an ACD to review or update	As a Professional user, I want to access ACD uptake and usage data, so that I can make evidence-based decisions on service improvements.	• NHS professional user • Other professional user	No

In scope MVP functionality

This project allows Facilitators who have been onboarded by the KCL Research Team to authenticate for purposes of the Thalamos eMHA platform and launch a Digital ACD. The Facilitator can invite other Clinicians and Non-Professional users to authenticate and contribute to the Digital ACD. This diagram demonstrates in-scope MVP functionality on Thalamos:



- **Establishing Service user context**

  The Thalamos Service user model requires users of the eMHA platform to establish a Service user context before they can create a workflow. Before an ACD can be created, the Facilitator must therefore establish the context of the Service user. This is important to allow Service user focused pathways to be developed. To establish the Service user context, the Facilitator can search a directory of Service users that exist on the Thalamos system using a minimum search criterion of surname and date of birth (the user can select age range if date of birth is unknown). If the Service user already exists on the system, the Facilitator can select the Service user and create an ACD. If the Service user does not exist on the system, the Facilitator must add the Service user to the system before they are able to create an ACD. This ensures ACDs are always launched in the context of the Service user they are intended for.

- **User story 2: Launching a new ACD**

  Once the Service user context has been established, the Facilitator must decide whether they are completing Part 1 on behalf of the Service user or if they are inviting the Service user to complete Part 1 digitally as a guest user. These are the two key journeys that the Facilitator will be able to choose from within the MVP. If the Facilitator is completing on behalf of the Service user (expected to be the more common journey), the Facilitator will need to be with the Service user, either in-person or virtually. If the Facilitator has invited the Service user to complete Part 1, the Service user can complete this alone and independently, although this is not recommended as feedback indicates that collaborative completion offers therapeutic benefit to the Service user. The sections in Part 1 can be completed in any order and across multiple sittings if necessary.

- **User story 3: Contributing to an existing ACD**

  Studies examining advance decision making for people with severe mental illness consistently find that collaborative models are the most popular and successful.[3]

  A core part of the ACD process is facilitating collaborative input from the Service user, Clinician and Facilitator. In the ACD prototype pilot study this took the form of a meeting in which the treating Clinician, the Service user and family/friend discussed mental health treatment and care recommendations and the treating clinician completed a capacity assessment.[22] In the digital process before this meeting, Clinicians involved in creating the Digital ACD can be invited by the Facilitator to review Part 1. These users can access via username, password and multifactor authentication or via short-term 'guest' sessions to provide flexibility depending on how the implementation study is conducted. During the meeting, the Facilitator can start Part 2 and transparently complete the 'Mental health treatment and care recommendations' section while the Service user and Clinician discuss the crisis plan. This ensures that the Service user's requests and preferences for treatment are discussed in a context of clinical appropriateness and feasibility.

  Once Part 2 is complete, the Facilitator can invite the Clinician to review and complete Part 3: the assessment of mental capacity. This will usually occur during the meeting or very shortly afterwards and will record the capacity of the Service user to make care and treatment decisions at the time the ACD was created. If the Clinician concludes that the Service user does not have capacity or is unsure, the Clinician can still complete Part 3 and the ACD can be made on this basis. They can also decide to pause the ACD and revisit it at a time that the Service user does have capacity. After the Clinician has completed the capacity assessment, the Facilitator is notified and can complete Part 4, recording any other views and summaries of other consultations.

  Once Parts 1 to 4 are complete, the Facilitator is responsible for inviting each user to review and sign the ACD. Firstly, the Clinician can be invited to sign Part 5. This Clinician can be the same Clinician who completed the capacity assessment or a different Clinician. Then, the Facilitator must invite the Service user to sign Part 6. If the Service user cannot access the form digitally, they can sign on the Facilitator's device. After the Clinician and the Service user have signed Part 5 & 6, Part 7 must be signed by the Facilitator to confirm all steps have been gone through. Only once all three users have signed the ACD will it be considered as complete. The ACD cannot be

edited after it has been completed. Each contributor will be notified and will be able to view and download a PDF of the ACD.

- **User story 4: Accessing an ACD at the point of clinical decision making**

  The MVP produces an ACD in PDF document format only. Users with access to the ACD can view this within the Digital ACD MVP or download a PDF copy and store/distribute it by other means outside of the MVP, such as SLaM's ePJS. For an implementation study, Professional Users involved can authenticate within the Digital ACD MVP to access existing ACDs for Service users or to another system where a PDF version has been stored.

  For a Digital ACD to fulfil its purpose, it must must appear at the point of need in a relevant system which the person who requires sight of it has access to. Whilst User Story 4 is included here as 'In Scope' as described above, the real value for this requirement will be delivered via integrations with other systems. As integrations are not in scope for this project, the Interoperability Requirements chapter discusses the options for surfacing Digital ACDs in other systems in more detail to ensure access at point of need, rather than just attaching PDFs to those systems.

  The Pan-London MHA digitisation programme will give clinicians across London access to the Thalamos eMHA platform when completing Mental Health Act (MHA) assessments. Thalamos eMHA can flag the existence of an ACD to any Mental Health Professional when they establish the Service user context before completing their assessment. Thalamos is a supplier to the Metropolitan Police Service, fulfilling admissions to hospital via police under Section 136 of the Mental Health Act. It is very unlikely that Service users would want police services to have access to their ACD, however Thalamos eMHA can flag the existence of an ACD to Police Users authenticating within the system in order to sign post them to relevant healthcare teams to consider less restrictive routes to care than Section 136.

Out of scope MVP functionality

These are the user stories that are not in scope of the Digital ACD MVP but must be considered for implementation beyond this project.

- **User story 1: Requesting a new ACD to be created**

  The MVP would require a Facilitator to lead the creation of a new ACD and most Service users are anticipated to engage with an ACD with active facilitation. However, Service users may simply ask the Facilitator to enable them to start the process on their own. This could be a Service user, or a stakeholder acting for the Service user. This is not in scope of this project but should be considered as part of an Implementation study to ensure the right to an ACD is one that Service users can exercise. Consideration will need to be given to how and when to outreach to Service users who have been detained under the MHA if a statutory duty to offer an ACD to that group is included in the MHA.

- **User story 5: Requesting updates to an ACD**

  The Digital ACD will include a date it should be reviewed, or circumstances may change which require the ACD to be amended or updated. This supports the development of a digital process whereby a Service user can signal a need to update an ACD and where review dates signal an action.

  Consideration should be given to how versions of these ACDs are updated wherever they are being surfaced in other systems to ensure data accuracy and avoid PDF version of forms being surfaced which are out of date. Direct integrations with other systems will mitigate the risk presented by multiple versions of PDFs being attached to different systems by ensuring those systems access the current document rather than older versions of a document.

- **User story 6: Locating an ACD to review or update**

  For the scope of this project, Facilitators and Clinicians will manage the creation of a new Digital ACD if one is required. However, Service user access and authentication to a digital service should be considered to allow Service users to notify professional users of circumstances such as a change in lifestyle or preferences. Again, the scope of this will depend on the service being used to provide Service user access.

- **User story 7: Data & insights**

  ACD uptake and use must be monitored to identify inequalities in take up and areas where more support is required. Previous studies recommend the following as key metrics to measure.[22]

  - Number of ACDs offered
  - Number of ACDs created
  - Demographics of those creating ACDs (matched to local population)
  - Number of ACDs accessed in crisis
  - Number of ACDs acted upon
  - Number of ACDs overridden

  Digitising ACDs presents multiple opportunities for the collection of data. Not only could the uptake of ACDs be monitored effectively, but valuable insights to demographic information, such as ethnicity, and common care preferences could be used to inform future MHA decision-making. Considerations will need to be given to data protection as ACDs will contain highly sensitive personal data.

Interoperability requirements

Successfully achieving the overall objectives of ACDs will ultimately rely on their interoperability with other systems. Integrations with third party software systems will enable different users to seamlessly access and contribute at necessary points along the ACD user journey. Furthermore, the data produced can be used to generate valuable insights through mechanisms such as dashboards and other reporting tools.

For NHS Professional Users

- **User Story 2: Launching a new ACD**

  In the scope of this project, a Facilitator is responsible for creating a new ACD before any other users can contribute. To access the digital ACD MVP, Facilitators must have an application-specific username and password to authenticate. While this is suitable for the purpose of an implementation study, requiring professional users at scale to retain multiple sets of credentials to sign into different applications can delay access and lead to security-related vulnerabilities. The administrative burden of password reset requests from users who have forgotten credentials can also be costly for the service desks resolving those queries.

  - **Single-sign On**

    In the scope of this project, a Facilitator is responsible for creating a new ACD before any other users can contribute. To access the digital ACD MVP, Facilitators must have an application-specific username and password to authenticate. While this is suitable for the purpose of an implementation study, requiring professional users at scale to retain multiple sets of credentials to sign into different applications can delay access and lead to security-related vulnerabilities. The administrative burden of password reset requests from users who have forgotten credentials can also be costly for the service desks resolving those queries.

  - **Launch options**

    Once successfully authenticated at the organisation level via SSO, a professional user could launch a digital ACD through the following systems:

    - EPR (eg. ePJS)
    - Specialist eMHA system (e.g. Thalamos eMHA)
    - ACD application

    Each of the options would require the professional user to specify the Service user context before starting a digital ACD; an important feature for audit purposes and reducing the risk of error by ensuring documentation is created for the correct Service user.

    Clinicians could access a stand-alone ACD application independently of other systems. However, professional and non-professional users could realise greater benefit from an integration between the ACD application and ePJS that would allow ACDs to be launched directly from the Service user context established in the EPR. Keeping ACD launch-capability to a single service rather than multiple applications would reduce complexity for clinicians and contribute to a more cohesive service. Furthermore, specified ACD fields could be auto-populated with Service user data if launched within context, reducing likelihood of errors and time spent inputting information.

    If there were a move to deploy across a system, Thalamos eMHA provides a flexible model which can be adapted to existing organisation and team structures to facilitate Service user search and ACD launch by Facilitators (or other relevant professionals).

- **User Story 4: Accessing an ACD at the point of clinical decision making**

This project highlights access to up-to-date ACDs at the point of clinical decision making as a central challenge to ACDs achieving their purpose. Ensuring that necessary stakeholders are aware that a Service user has an ACD in place raises further considerations for wider implementation, especially across different organisations and regions.

The Digital ACD MVP produces an ACD in PDF document format, which can be accessed through the ACD application or downloaded locally by a user and uploaded to a separate system, such as an EPR. Information can then be uploaded from the EPR to a Shared Care Record (ShCR). Unlike local EPRs, ShCRs are designed to be accessible by clinical staff across multiple organisations and facilitate joined-up care as a Service user moves between different parts of the health and social care system. This suggests they could be a suitable location for accessing ACDs at the point of clinical decision making.

However, the current PDF format poses two key challenges: inter-system version control and local storage of sensitive Service user data and access by people with MHA training. Due to the static nature of PDF documents, making updates to existing ACDs would be cumbersome and raises questions around version control; in order for the latest Service user preferences to be accessed at the point of clinical decision making, all other PDF versions in existence would need to be erased and replaced. Moreover, the need for a user to download a PDF copy locally raises information governance concerns around security of Service user data. The MVP and PDF output is highly portable and provides flexibility to facilitate the goals of this project and implementation study. Software development is an iterative process and interoperability with other digital systems should be explored to surface data in a format which mitigates risks with version control and local storage.

While EPR integrations are suitable for Service user-context ACD launch, interoperability between the ACD application and a ShCR would allow structured data to move between the two services, removing the dependency on manual PDF uploads and enabling professional users to push the most recent version of an ACD directly to the ShCR, whilst replacing out-dated versions. Therefore, all professional users with access to the ShCR would be able to view an up-to-date, read-only version of the ACD. A version-control strategy would need to be implemented; however, ShCR integration is an opportunity to move away from storing digital ACDs as PDF documents and offers a more dynamic, accessible approach to locating up to date ACDs at the point of clinical decision making. Further consideration needs to be given to:

- Service users who have objected to their data being part of the ShCR.
- Understand which ShCR would be the most suitable for giving stakeholders the means to readily locate ACDs at the point of clinical decision making. One London, for instance, could fulfil this role for clinicians within London's five Integrated Care Systems and the London Ambulance Service. Beyond London, further consideration needs to be given to which systems may be appropriate

Thalamos is the preferred supplier for the Pan-London Mental Health Programme. Once rolled out, all mental health professionals in the region will access Thalamos eMHA to complete Mental Health Act assessments. The eMHA requires a Service user context to be established before a Mental Health Act Assessment can be completed. Integrating with this system at point of Service user identification provides a tangible opportunity to flag the existence of an ACD immediately before a Mental Health Act assessment. If an ACD is not in place, Thalamos eMHA could also support clinicians in offering Service users the option to create one.

There may also the need to consider accessing ACDs at other relevant points of decision-making. For instance, Thalamos 136 also provides the Digital Section 136 solution for the Metropolitan Police Service (MPS). Whilst there are ethical considerations integrating with police systems, there is an opportunity to vastly improve signposting to relevant health professionals. Currently MPS call a generic phone number for healthcare advice when responding to a Section 136. Integration with a Digital ACD could provide a vastly more targeted referral to teams who know the Service user and offer less restrictive routes to Police rather than detaining under Section 136 of the Mental

Health Act. This will support initiatives such as Right Care Right Person; a model designed to ensure that when there are concerns for a person's welfare linked to mental health, medical or social care issues, the right person with the right skills, training and experience will respond.

Beyond London, Thalamos CQC could provide the Care Quality Commission with a means to monitor ACD uptake and usage nationally. Regardless of the supplier of digital ACDs, there would still be value to Professionals and Non-Professionals in integrating with Thalamos eMHA products.

- **User Story 3: Contributing to an existing ACD**

  Similarly to launching a new ACD, EPR integrations could provide a means for Professional Users to contribute, renew and update existing ACDs. Given the potential for therapeutic benefit from the collaborative relationships between professional users and non-professional users, the ability to change information is likely to sit within a Service user's local GP, social care or hospital computer system that is responsible for facilitating the creation of the ACD. Consideration should be given to which specific professional users are able to edit a Service user's ACD, but this approach would ensure that there are organisation-level restrictions on who can contribute to an existing ACD.

  There will need to be a mechanism in place to notify professional users when amends to the ACD are required. For example, the ACD may need to be renewed periodically or a Service user may need to request to make an update based on a change in personal circumstances (options to be explored in a later chapter). Although not in scope of the digital ACD MVP, an ACD application integrated with an EPR could automatically notify professional users when changes need to be made and flag approaching review dates.

For Non-professional Users

The digital ACD MVP does not allow non-professional users to launch a new ACD independently of a Facilitator and it does not provide for the creation of a legally binding Advance Decision to Reduce Treatment (ADRT) relating to physical health treatment. The scope of this project would require a Service user to express the wish to create an ACD to a Facilitator, who would then be responsible for ensuring it is completed as per the structure outlined. This delivers on the project aims to encourage clinical engagement as well as integrating ACDs within clinical record systems.

From an ethical standpoint, a Service user-centric approach is a key aim of ACDs and attention should be given to interoperability that could promote autonomy. Standardised Service user engagement tools, such as the NHS App or NHS Log In should be considered to avoid digital localisation becoming a challenge as non-professional users move between organisations and/or Integrated Care Systems. This section considers three possible options for independent ACD management by non-professionals users to request, complete and access their digital ACD from one place. It is important to note that research so far has not evaluated the efficacy of these options and further study should be carried out to understand how they would integrate with clinical record systems.

- **NHS application**

  An integration between the ACD application and the NHS application would allow non-professional users with NHS accounts to access their health record and participate in the creation of an ACD. This could be achieved via a web-integration, whereby a user would launch a "white-labelled" digital ACD viewer within the NHS application. As well as reducing time pressures on professional users, such as Facilitators, providing better access to health records will help Service users to better understand and manage their health, leading to better health outcomes and improved Service user and health staff satisfaction. However, this approach would require extensive design collaboration between the digital ACD supplier and NHS digital, which could create disjointed user experience between the different systems. Moreover, consideration needs to be given to those users that do not have an NHS application account (at the time of writing, 68% of people in England are registered with the NHS App). If the overwhelming drive is to reduce disparity in health, access cannot be (entirely) through the NHS application.v

- **NHS Login**

  An alternative to integrating with the NHS application is using NHS Login. NHS Login is an integration approach that allows non-professional users to access multiple digital health services using a single set of NHS login account credentials. This would provide users with a simple, trusted and re-usable way to access an ACD application, removing the need to set up credentials specifically for the purpose of ACDs. The user would authenticate securely via NHS Login and, if they were a new user, be required to verify their identity. Once authenticated, non-professional users could contribute to their own ACD or view ACDs that they have been named as a key contact for.

- **Trust-based Service user portals**

  Trust-based portals could also support Service users to take a more active role in managing ACDs. 'Beth,' for example, is a personal health record developed for Service users using SLaM services. It is designed to enhance interaction and information sharing between SLaM staff, Service users and carers, providing Service users with access to parts of the electronic clinical record. Non-professional users could contribute to an ACD or communicate their preferences with professional users within the application. However, Trust-based systems may be limited in terms of scalability because non-professional users would need to be registered with that specific Trust in order to access. Scaling Trust-based systems beyond the Trust to create a more inclusive approach to ACDs would need to be considered. Level of uptake of Trust-based platforms would also need to be examined.

Data & insights

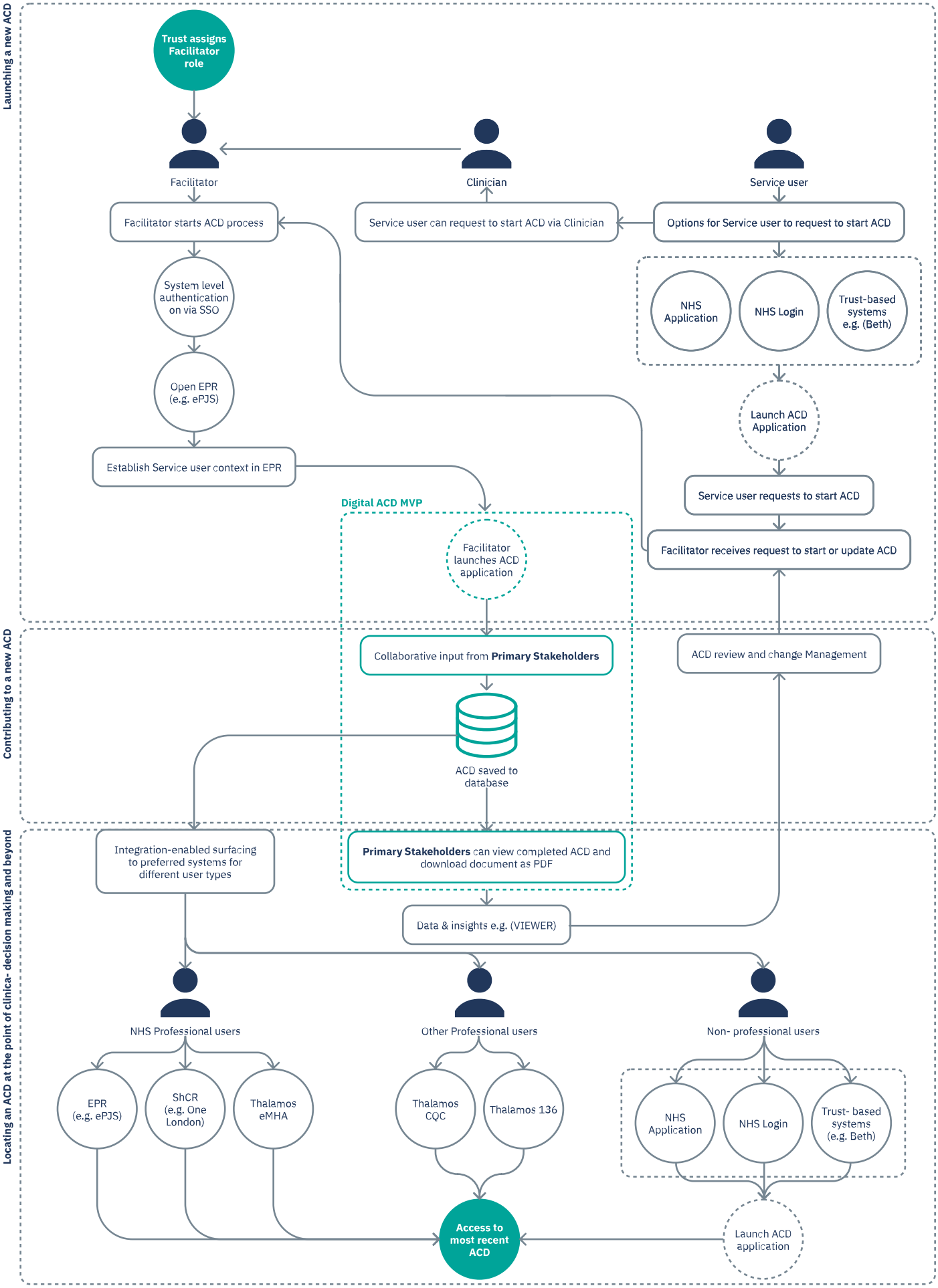
The opportunity to generate valuable insights through digitisation is crucial to demonstrating the advantages of introducing ACDs into mental health care and building on the empirical and ethical findings established by ACD research so far. Digital tools significantly increase the efficiency and accuracy of data collection, enabling analysis of real-time data and allowing for a more customisable approach to data visualisation. Systems in isolation, such as a standalone ACD application, would allow for data collection specific to the use of ACDs, which would provide useful insights to basic numerical metrics such as number of ACDs created, general uptake and demographics.

To realise the full potential of ACD data, integrations with other clinical systems, such as specialist eMHA providers, must be considered. Combining data from multiple sources, rather than viewing in isolation, will allow for insights to be drawn across the entire mental health pathway at a far more sophisticated level. Compatibility with the Mental Health Services Data Set (MHSDS) will need to be explored if ACD data is to be submitted for use by other health organisations as a secondary dataset.

Furthermore, interactive systems such as SLaM's VIEWER that draw upon record sets such as CRIS and Cogstack to present aggregated population data to clinicians could provide useful insights relating to ACDs. For example, the ability to sub-divide the data according to populations of interest could be used to define 'at risk' groups who may benefit from intervention.[29]

System-level view of ACDs

The diagram on the following page demonstrates how the Digital ACD MVP could interoperate with other clinical and non-clinical systems to enhance benefit at three key stages: launching a new ACD, contributing to an existing ACD and locating an ACD at the point of clinical decision-making.


Launching a new ACD
Trust assigns Facilitator role
Facilitator
Clinician
Service user
Facilitator starts ACD process
Service user can request to start ACD via Clinician
Options for Service user to request to start ACD
System level authentication on via SSO
NHS Application
NHS Login
Trust-based systems e.g. (Beth)
Open EPR (e.g. ePJS)
Launch ACD Application
Establish Service user context in EPR
Service user requests to start ACD
Digital ACD MVP
Facilitator receives request to start or update ACD
Facilitator launches ACD application
Contributing to a new ACD
Collaborative input from Primary Stakeholders
ACD review and change Management
ACD saved to database
Integration-enabled surfacing to preferred systems for different user types
Primary Stakeholders can view completed ACD and download document as PDF
Data & insights e.g. (VIEWER)
Locating an ACD at the point of clinica- decision making and beyond
NHS Professional users
Other Professional users
Non- professional users
EPR (e.g. ePJS)
ShCR (e.g. One London)
Thalamos eMHA
Thalamos CQC
Thalamos 136
NHS Application
NHS Login
Trust- based systems (e.g. Beth)
Access to most recent ACD
Launch ACD application

Deployment considerations

There are key workstreams to explore ahead of any digital ACD implementation study and wider operational use. While the scope of digital ACD usage will define the specific workstreams required, the Digital Technology Assessment Criteria (DTAC) provides a useful framework for assessing an approach to deployment and the workstreams required against national baseline criteria for digital health technologies. The key workstreams are examined below.

Information governance and data sharing

Consideration needs to be given to the way information related to ACDs will be handled to ensure Service user, personal and sensitive data is managed securely and confidentially. As the transition to digital ACDs changes the way data is processed, a Data Protection Impact Assessment (DPIA) must be completed to identify and mitigate the associated risks. This will also be essential for demonstrating compliance with the UK General Data Protection Regulation (GDPR), in line with the following data protection principles that make sure information is:

- Used fairly, lawfully and transparently
- Used for specified, explicit purposes
- Used in a way that is adequate, relevant and limited to only what is necessary
- Accurate and, where necessary, kept up to date
- Kept for no longer than is necessary
- Handled in a way that ensures appropriate security, including protection against unlawful or unauthorised processing, access, loss, destruction or damage

A DPIA is the responsibility of the data controller – the organisation that decides 'why' and 'how' personal data is processed – to complete. The processor of this data, in this case the supplier of a digital ACD, may also be able to assist. This would need to be actioned before the use of any digital variation of an ACD, including the use of the ACD MVP in an implementation study. For any wider use beyond this, there would be a need to review and update the DPIA beforehand. Furthermore, under the Data Protection Act 2018, data subjects do have a right to find out what information organisations store about them. Consideration should therefore be given to allowing people to exercise their right to access, amend or erase data if necessary. This could be detailed in a publicly available privacy policy and people must be able to exercise their rights in a digital ACD.

Data sharing agreements between the organisations involved in the implementation of ACDs will also need to be examined. Complexity arises where Primary and Secondary stakeholders belong to a variety of different organisations. Similarly, to authentication, this advocates a system-level approach to data sharing as agreement by ICBs to implement ACDs would negate the need for individual agreements between NHS Trusts and non-NHS organisations. System-led data sharing agreements will help all parties involved to set clear standards pertaining to roles and responsibilities, demonstrating adherence to accountability obligations under UK GDPR.

Clinical safety and actionable insights

Measures to ensure that effective clinical risk management is carried out in the development and deployment of digital ACDs will need to be ensured. As the digital ACD will be used to influence, support, and manage the care of Service users', a DCB0129 and DCB0160 clinical safety standard must be completed prior to being operationalised and periodically after each lifecycle to demonstrate clear hazard auditing. The following points outline what is required from each organisation:

- The organisation that is responsible for the development and maintenance of a digital ACD system (i.e. the supplier) will be required to complete a DCB0129 to evidence the clinical safety of the product. This will involve the creation of a Hazard Log, Clinical Safety Case Report and Clinical Risk Management Plan, as well as any other supporting tools that are deemed necessary.

- The organisation that is responsible for the deployment and use of a digital ACD system (i.e. KCL/SLAM) will be

required to complete a DCB0160 to ensure the effective application of clinical risk management.

Some examples of potential clinical safety risks identified in the digital ACD MVP in consultation with Thalamos' Clinical Safety Officer are outlined below. These have not been risk assessed at this point but highlight actionable clinical insights for consideration:

Ref.	Example of risk to consider	Description of risk in MVP
1	Professional Users misunderstanding what an ACD is and why it exists	The risk is that the legal status of an ACD may be misunderstood by clinicians. Adverse outcomes could occur in two directions. Firstly, there is the risk that the responsibility to access the document and take the contents seriously when making care and treatment plans is not understood. This might mean well considered and beneficial plans are not employed to the Service user's, family and clinical team's detriment. Secondly there is the risk that the document is accessed but is 'blindly' applied without full consideration of the present situation e.g. if there are unanticipated circumstances or choices made in the ACD might now have harmful outcomes.
2	Medical inaccuracy of ACDs	The ACD should not be relied on as the sole source of clinical information such as diagnosis or medications. Its main function is to provide information on the person's care preferences. This is because a facilitator may not have the most accurate full medical diagnosis, or the Service user may not know or agree with their diagnosis. If no other information from EPRs is available (e.g., the Service user presents to a different trust), a small inaccuracy could impact the risk assessments or mental health act assessments that rely on this information. If an inaccurate diagnosis is recorded and applied, the outcome can be vastly different based on a Clinician's understanding of the nature of the condition. This could also apply to the medical information on ACDs being outdated if a versioning strategy is not in place.
3	Lack of training for Professional Users using ACDs	Variation in the clinical and digital capabilities of users of digital ACDs could contribute to the scenarios identified in risks 1 and 2. This risk explored further in the Stakeholder training section.
4	Potential for ACDs to breach the level of Electronic Health Records (EHR) and classify as medical devices	The creation of digital ACDs and consequent sharing with multiple agencies could result in ACDs forming part of a Service user's EHR. This could be used to influence medial decisions and there is a need to determine whether digital ACDs would classify as medical devices. If so, further due diligence and registration with UK MHRA would be required.

Testing to embed user centred design

Throughout its development, the digital ACD MVP has been stress-tested using a variety of real-world scenarios from previous studies. While proving that the MVP can facilitate the creation ACDs successfully, there is a need for more rigorous User Acceptance Testing (UAT) to embed lived experience and clinical safety by design, and to identify any issues with the software before it is used operationally. Due to the time constraints of this project, in-depth user testing was not possible, however, this could form part of an implementation study.

A UAT plan should move beyond reliance on retrospective real-world scenarios and directly involve stakeholders who will be using the software day to day. This will require the development of test cases: step-by-step instructions that describe the conditions and variables under which a tester will examine if the digital ACD MVP can be used to complete goals correctly. Collectively, test cases should be comprehensive enough to cover the known high-level requirements identified in the Digital MVP section of this document. Any additional scenarios that are discovered during UAT should be recorded and highlighted as areas for improvement.

Stakeholder training

Consideration must be given to the level of training required for Professional User categories to utilise digital ACDs effectively. In most cases, Professional Users – particularly Facilitators and Clinicians – will be responsible for guiding a Service user through the experience of ACD creation and disseminating preferences through other digital systems

highlighted in the Interoperability section of this document. Given the sensitive nature of information documented in ACDs and the potential for it to influence treatment and care, user training is important to ensure the safety of Service users and to maintain high standards of care quality. Three key areas for training plans to address are:

- **Make**

  Guidance that supports collaboration between Professional and Non-professional users to complete ACDs and enhance therapeutic alliance. Guidance on the new role of facilitator in the process.

- **Access**

  Guidance that ensures Professional workforces are comfortable with locating digital ACDs, particularly at the point of clinical decision making. This highlights the need to consider digital literacy and the ability of users to meet the needs of their local population effectively.

- **Apply**

  Guidance that engrains the necessary behaviours, attitudes and knowledge required to maximise respect for Service user decision-making. This could include implementation of standard operating procedures specific to the use of ACDs.

Depending on the degree of interoperability between digital ACDs and other digital systems, some thought should also be given to the training that may be required for stakeholders to achieve operational goals without integrations. This will apply to user training for the Digital ACD MVP.

Benefits case

Documents like ACDs have the potential to reduce the number of compulsory admissions under MHA by 23-25%.[11, 12] Ahead of wider implementation, consideration should be given to the creation of a benefits case that highlights the potential opportunity for bed day cost saving. Although cost savings are not the primary goal of ACDs, the potential for ACDs to reduce compulsory MHA admissions could have financial implications that support an economic argument for supporting implementation. Due to the high cost of bed days, a relatively small reduction in admissions is sufficient to make a significant financial impact. Digitisation is likely to make efficiencies with implementation therefore maximising likely financial impact.

The following example gives a high-level estimate of bed day cost savings nationally if MHA admissions were reduced by 10% and 20%. This is based on an average length of stay of 90.91 days and an average bed day cost of £422.[32] In this example, the average cost per Service user detained under MHA is £38,364.

Reduction in MHA admissions by	Total Annual MHA admissions (annually)	Total bed days saved (annuall)	Total cost saving (annually)
0%	53,239	-	-
<10%	47,915	484,005	£204,250,110
<20%	42,591	968,010	£408,500,220

These type of calculations are necessarily crude. However, they could be used to create monetary targets for ACDs to evaluate their implementation (and digitising would enable them). However, they must be balanced with the need to collect data on non-monetary benefits such as improved Service user experience, therapeutic alliance and bespoke care and treatment plans. Digitisation can bring efficiencies with non-monetarised data collection also.

Discovery document summary

Research so far has evidenced the potential for ACDs to deliver benefits to mental health care (from both ethical and empirical points of view). The key ethical arguments for ACDs are that they are an effective tool for promoting the personal autonomy of someone living with mental illness, improving well-being and building therapeutic alliance. Empirically, ACDs significantly reduce involuntary hospital admissions by sign-posting alternative routes to care and treatment, as well as enhancing therapeutic alliance between Clinicians and Service users. As a direct result of this evidence, ACDs have been a central issue covered in the Independent Review of the Mental Health Act and the Joint Parliamentary Committee report on the Draft Mental Health Act Bill.

While there is emerging legislative support for the promotion of ACDs, clinical engagement coupled with accessibility issues remain challenging to implementation. We propose that digital ACDs are a safe and secure method to surface necessary information to the relevant stakeholders at the point of clinical decision-making. This is a practical way for ACDs to deliver their intended purpose whilst removing the barriers to implementation. Integrations with clinical and non-clinical systems offer a viable means to launch and manage digital ACDs, while the data gathered can be used to test impact in line with the goals of Mental Health Act reform. Crucially, an ICB level approach to digital ACD implementation would facilitate unified, inter-organisation co-operation and maximise the potential for primary and secondary stakeholder engagement.

To understand how digital ACDs will work at a system-level, a digital ACD MVP has been collaboratively developed by KCL and Thalamos for use in an implementation study. The Deployment Considerations section of this document highlights the key workstreams that need to be explored ahead of any further operational use: information governance and data sharing, clinical safety, testing and stakeholder training. Findings from further research using the MVP will be used to inform digital ACD product improvements and demonstrate the benefits of system-level implementation.

Glossary of terms

Term	Definition
ACD Application	The concept of a stand-alone ACD Application, such as a web portal, that would be independent of other systems. The current Digital ACD MVP is accessed via Thalamos eMHA but for the purposes of this document an ACD application is considered as a separate product.
Advance Choice Document (ACD)	A document outlining a Service user's advance decisions to care and treatment specifically in relation to the use of the mental health act. The Joint Parliamentary Committee on the Mental Health Bill says Service users should have a statutory right to request an ACD. This should not be confused with Advance Decisions for other types of health and care.
Advance Statements Project for Black African and Caribbean (AdStAC)	A KCL research project that is developing and implementing advance statements for Black African and Caribbean people who have previously been detained under the Mental Health Act.
Authentication	The process of verifying the identity of a user before they can access a digital system. In doing this, authentication allows a system to grant access to the right user at the right time with confidence and assures secure systems, secure processes, and information security. Security can be improved through methods such as multi-factor authentication (MFA), which requires users to pass multiple verification factors, and Single Sign-On (SSO). See also Role Based Access Control (RBAC)
Authorisation	The process of determining whether a user is allowed to access a system or perform a specific action within a system. Authorisation tools can facilitate RBAC that can be managed centrally, assigning different permissions to different users. See also RBAC.
Beth	A digital interface created by South London and Maudsley NHS Foundation Trust which allows Service users to record and track health goals, access care plans, view appointments and message care teams.
Clinical Record Interactive Search (CRIS)	A system developed for use at the NIHR Maudsley Biomedical Research Centre. Provides authorised researchers with regulated access to anonymised information extracted from the South London and Maudsley NHS Foundation Trust (SLaM) electronic clinical records system.
Coordinate my care (CMC)	An NHS service that supports Service users in situations requiring urgent care by hosting an electronic, personalised, urgent care plan accessible to all health and social care professionals. This is created jointly by the Service user and their healthcare professional.
Crisis PACk	A prototype ACD in the form of a collaborative template. This has been used to pilot implementation strategies previously and informed the contents of the Digital ACD MVP used in this project.
Data Protection Impact Assessment (DPIA)	A requirement under UK GDPR that describes a process designed to identify risks arising out of the processing of personal data and to minimise these risks as far and as early as possible.
Digital ACD	A general term describing a digital version of an ACD.
Digital ACD MVP	This refers to the Thalamos-hosted ACD minimum viable product (MVP) that has been built for the purpose of this project. Currently, this utilises Thalamos eMHA infrastructure but may become a separate application in time.
Digital system	This refers collectively to all the elements of a software-based system, such as hardware, networks, and users. In this context, the digital system is the digital ACD.
Electronic Patient Journey System (ePJS)	SLaM electronic Patient record (EPR).
Electronic Patient Record (EPR)	Also known as Electronic Health Record (EHR). A repository of information regarding the health of a Service user in a computer processable format.
Empirical intervention	An activity undertaken to improve a person's health or care based on evidence rather than theory. See Chapter: Introduction.
Ethical intervention	An activity undertaken to improve a person health or care based on moral principles for doing so. See Chapter: Introduction
Integration	The process of combining multiple types of software systems to create a unified single system.
Interoperability	The capability of different software systems to exchange information with one another using a common set of protocols.

Term	Definition
Minimum Viable Product (MVP)	An early version of a product with just enough features to be usable. They are useful tools for validating product assumptions and gathering feedback, which enable evidence-based decision-making on product improvements.
Data Protection Impact Assessment (DPIA)	A requirement under UK GDPR that describes a process designed to identify risks arising out of the processing of personal data and to minimise these risks as far and as early as possible.
OneLondon	OneLondon is part of NHS England London. A service created in May 2018 to facilitate sharing of information across London to support fast, safe, effective care.
ReSPECT	The ReSPECT process creates personalised recommendations for a person's resuscitation and end of life plan in a future emergency in which they are unable to make or express choices. It is coordinated by the Resuscitation Council UK.
Role-based access control (RBAC)	A method of assigning permissions to users based on their role within an organisation. It offers a simple, manageable approach to access management and can be used to restrict system access to authorised users.
Service user	A term used to describe a person who is a patient or a user of services provided by health organisations. It is important to recognise that there are ongoing debates around the suitability of this term. While there is not a single term that has been met with universal support, 'Service user' is used in this document because it is factual, widely used and understood by most.
Shared Care Record (ShCR)	Shared Care Records, previously called Local Health and Care Records, are being introduced across England. These allow people involved in Service user care to access health and care records safely and securely across a region so that they can provide better joined-up care as people move between different parts of the health and social care system.
Single Sign-On (SSO)	A user authentication method that enables users to sign into a system once and securely access multiple independent software applications. For example, an SSO implemented at the ICB level could enable any users signed into organisations within that ICB to access an ACD application.
Summary Care Record (SCR)	Summary Care Records (SCR) are an electronic record of important Service user information, created from GP medical records. They can be seen and used by authorised staff in other areas of the health and care system involved in the Service user's direct care.
System Level	Processes which involve stakeholders from multiple organisations involved in the health and care of a Service user. Integrated Care Systems will facilitate governance structures for system level digital projects. Multiple systems may combine at a Regional Level.
Thalamos eMHA	An end-to-end digital workflow tool built specifically for stakeholders of the Mental Health Act (MHA). As a Thalamos-hosted product, it is seamlessly interoperable with all other Thalamos services, such as Thalamos CQC and Thalamos 136.
User	An individual, or group of individuals, who interact with a digital system. Different user types are defined in the Stakeholder section of this document.
Visualisation & Interaction With Electronic Records (VIEWER)	A digital tool developed by SLaM for visualising data in mental health records. VIEWER summarises population-level data on service usage, medications, psychological interventions, and physical health on an interactive platform.

References

[1] Owen G, Gergel, Stephenson L, Hussain O, Rifkin L, Keene AR. Advance decision-making in mental health–Suggestions for legal reform in England and Wales. International journal of law and psychiatry. 2019;64:162-77.

[2] Ward A. Enabling citizens to plan for incapacity: A review of follow-up action taken by member states of the Council of Europe to Recommendation CM/Rec (2009) 11 on principles concerning continuing powers of attorney and advance directives for incapacity. Council of Europe https://rm. coe. int/cdcj-2017-2e-final-rapport-vs-21-06 ...; 2017.

[3] Swanson J, Swartz M, Ferron J, Elbogen E, Van Dorn R. Psychiatric advance directives among public mental health consumers in five US cities: prevalence, demand, and correlates. Journal of the American Academy of Psychiatry and the Law Online. 2006;34(1):43-57.

[4] Hindley G, Stephenson LA, Keene AR, Rifkin L, Gergel T, Owen G. "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. 2019;4.

[5] Morriss R, Mudigonda M, Bartlett P, Chopra A, Jones S. 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. 2017.

[6] Thornicroft G, Farrelly S, Szmukler G, Birchwood M, Waheed W, Flach C, et al. Clinical outcomes of Joint Crisis Plans to reduce compulsory treatment for people with psychosis: a randomised controlled trial. The Lancet. 2013;381(9878):1634-41.

[7] Henderson C, Flood C, Leese M, Thornicroft G, Sutherby K, Szmukler G. Effect of joint crisis plans on use of compulsory treatment in psychiatry: single blind randomised controlled trial. BMj. 2004;329(7458):136.

[8] Ruchlewska A, Mulder C, Smulders R, Roosenschoon B, Koopmans G, Wierdsma A. The effects of crisis plans for patients with psychotic and bipolar disorders: a randomised controlled trial. BMC psychiatry. 2009;9(1):1-8.

[9] Papageorgiou A, King M, Janmohamed A, Davidson O, Dawson J. Advance directives for patients compulsorily admitted to hospital with serious mental illness: randomised controlled trial. The British Journal of Psychiatry. 2002;181(6):513-9.

[10] Lay B, Kawohl W, Rössler W. Outcomes of a psycho-education and monitoring programme to prevent compulsory admission to psychiatric inpatient care: a randomised controlled trial. Psychological medicine. 2018;48(5):849-60.

[11] de Jong MH, Kamperman AM, Oorschot M, Priebe S, Bramer W, van de Sande R, et al. Interventions to reduce compulsory psychiatric admissions: a systematic review and meta-analysis. JAMA psychiatry. 2016;73(7):657-64.

[12] Molyneaux E, Turner A, Candy B, Landau S, Johnson S, Lloyd-Evans B. Crisis-planning interventions for people with psychotic illness or bipolar disorder: systematic review and meta-analyses. BJPsych Open. 2019;5(4).

[13] Swanson JW, Swartz MS, Elbogen EB, Van Dorn RA, Ferron J, Wagner HR, et al. Facilitated psychiatric advance directives: a randomized trial of an intervention to foster advance treatment planning among persons with severe mental illness. American Journal of Psychiatry. 2006;163(11):1943-51.

[14] Farrelly S, Lester H, Rose D, Birchwood M, Marshall M, Waheed W, et al. Improving therapeutic relationships: joint crisis planning for individuals with psychotic disorders. Qualitative Health Research. 2015;25(12):1637-47.

[15] Barnett P, Mackay E, Matthews H, Gate R, Greenwood H, Ariyo K, et al. Ethnic variations in compulsory detention under the Mental Health Act: a systematic review and meta-analysis of international data. The Lancet Psychiatry. 2019;6(4):305-17.

[16] Wessely S, Gilbert S, Hedley M, Neuberger J. Modernising the Mental Health Act. Department of Health and Social Care; 2018.

[17] Barrett B, Waheed W, Farrelly S, Birchwood M, Dunn G, Flach C, et al. Randomised controlled trial of joint crisis plans to reduce compulsory treatment for people with psychosis: economic outcomes. PloS one. 2013;8(11):e74210.

[18] Ross S, Scholin, L., MacLeod, C., Chopra, A. Advance Statements in Scotland. Mental Welfare Commission for Scotland; 2021.

[19] Shields LS, Pathare S, van der Ham AJ, Bunders J. A review of barriers to using psychiatric advance directives in clinical practice. Adm Policy Ment Health. 2014;41(6):753-66.

[20] Farrelly S, Lester H, Rose D, Birchwood M, Marshall M, Waheed W, et al. Barriers to shared decision making in mental health care: qualitative study of the Joint Crisis Plan for psychosis. Health Expectations. 2016;19(2):448-58.

[21] Stephenson LA, Gergel T, Keene AR, Rifkin L, Owen G. The PACT advance decision-making template: preparing for Mental Health Act reforms with co-production, focus groups and consultation. International journal of law and psychiatry. 2020;71:101563.

[22] Stephenson LA, Gergel T, Ruck Keene A, Rifkin L, Owen G. Preparing for Mental Health Act reform: Pilot study of co-produced implementation strategies for Advance Choice Documents. Wellcome Open Research. 2022;7:182.

[23] Ruchlewska A, Wierdsma AI, Kamperman AM, Van Der Gaag M, Smulders R, Roosenschoon B-J, et al. Effect of crisis plans on admissions and emergency visits: a randomized controlled trial. PloS one. 2014;9(3):e91882.
[24] Ruchlewska A, Mulder C, Van der Waal R, Kamperman A, Van der Gaag M. Crisis plans facilitated by patients advocates are better than those drawn up by clinicians: results from an RCT. Administration and Policy in Mental Health and Mental Health Services Research. 2014;41(2):220-7.

[25] Tinland A, Loubière S, Mougeot F, Jouet E, Pontier M, Baumstarck K, et al. Effect of Psychiatric Advance Directives Facilitated by Peer Workers on Compulsory Admission Among People With Mental Illness: A Randomized Clinical Trial. JAMA psychiatry.

[26] Sherman PS. Computer-assisted creation of psychiatric advance directives. Community mental health journal. 1998;34:351-62.

[27] Care Cm. Coordinate my Care activity updates 2021 [Available from: https://createsend.com/t/j-FAA339C99577404E2540EF23F30FEDED.

[28] Gill R, Stephenson LA, Owen G, Droney J. Digital advance decision making for people with severe mental illness. In progress.

[29] Codling, D., 2021. VIEWER: A Digital tool for visualising data in mental health records, London: s.n.

[30] Stephenson, L., Gergel, T., Owen, G. & Ruck Keene, A., 2019. The future of Advance Decision Making in the Mental Health Act. London: The Policy Institute.

[31] NHS Digital, 2023. NHS app hits over 30 million sign ups. URL: https://digital.nhs.uk/news/2023/nhs-app-hits-over-30-million-sign-ups

[32] MHSDS, NHS Digital. Office for National Statistics. Census Population Estimates, 2017

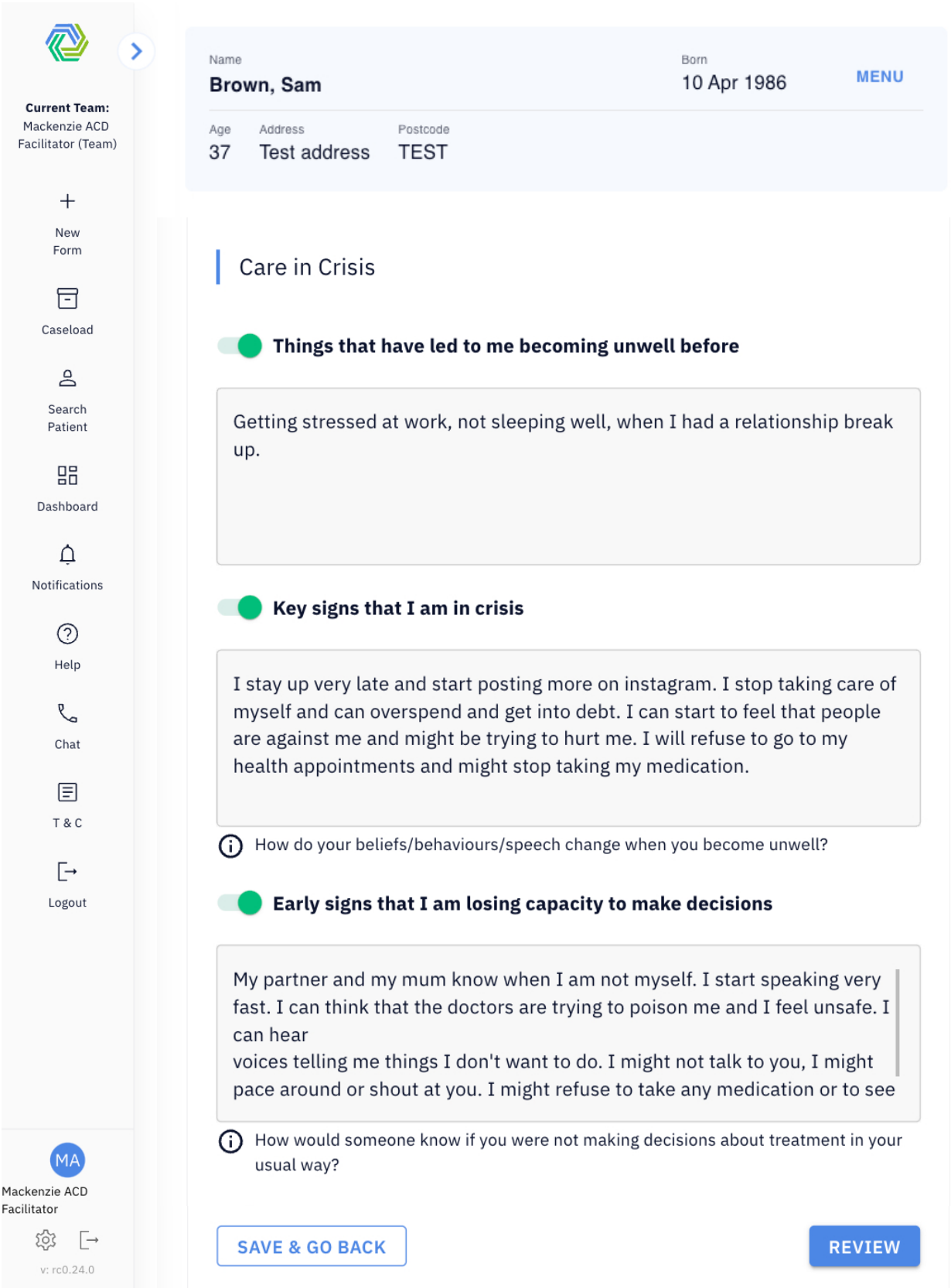
[33] Joint Committee on the Draft Mental Health Bill 2022. Published by the Authority of the House of Commons and the House of Lords. 2023: 82

[34] Stephenson, L., Gieselmann, A., Gergel, T., Owen, G., Gather, J., Scholten, M. ‘Should self-binding directives be implemented in psychiatric practice?: A systematic review of reasons In progress

Appendix: Digital ACD MVP interface

Example 1A: Care in Crisis interface

The Facilitator and Service user can collaboratively complete details about preferences for care and treatment. Information tooltips provide helpful prompts to the type of information that is useful to include and toggles by each question enable users to opt in or out of answering.



Example 1B: Care in Crisis PDF

Demonstration of how the information entered in Example 1A is displayed in the final PDF document.

NHS Number: unknown at time of completion

Care in Crisis

Things that have led to me becoming unwell before

Getting stressed at work, not sleeping well, when I had a relationship break up.

Key signs that I am in crisis

I stay up very late and start posting more on instagram. I stop taking care of myself and can overspend and get into debt. I can start to feel that people are against me and might be trying to hurt me. I will refuse to go to my health appointments and might stop taking my medication.

Early signs that I am losing capacity to make decisions

My partner and my mum know when I am not myself. I start speaking very fast. I can think that the doctors are trying to poison me and I feel unsafe. I can hear voices telling me things I don't want to do. I might not talk to you, I might pace around or shout at you. I might refuse to take any medication or to see health professionals.

Key things I want to avoid

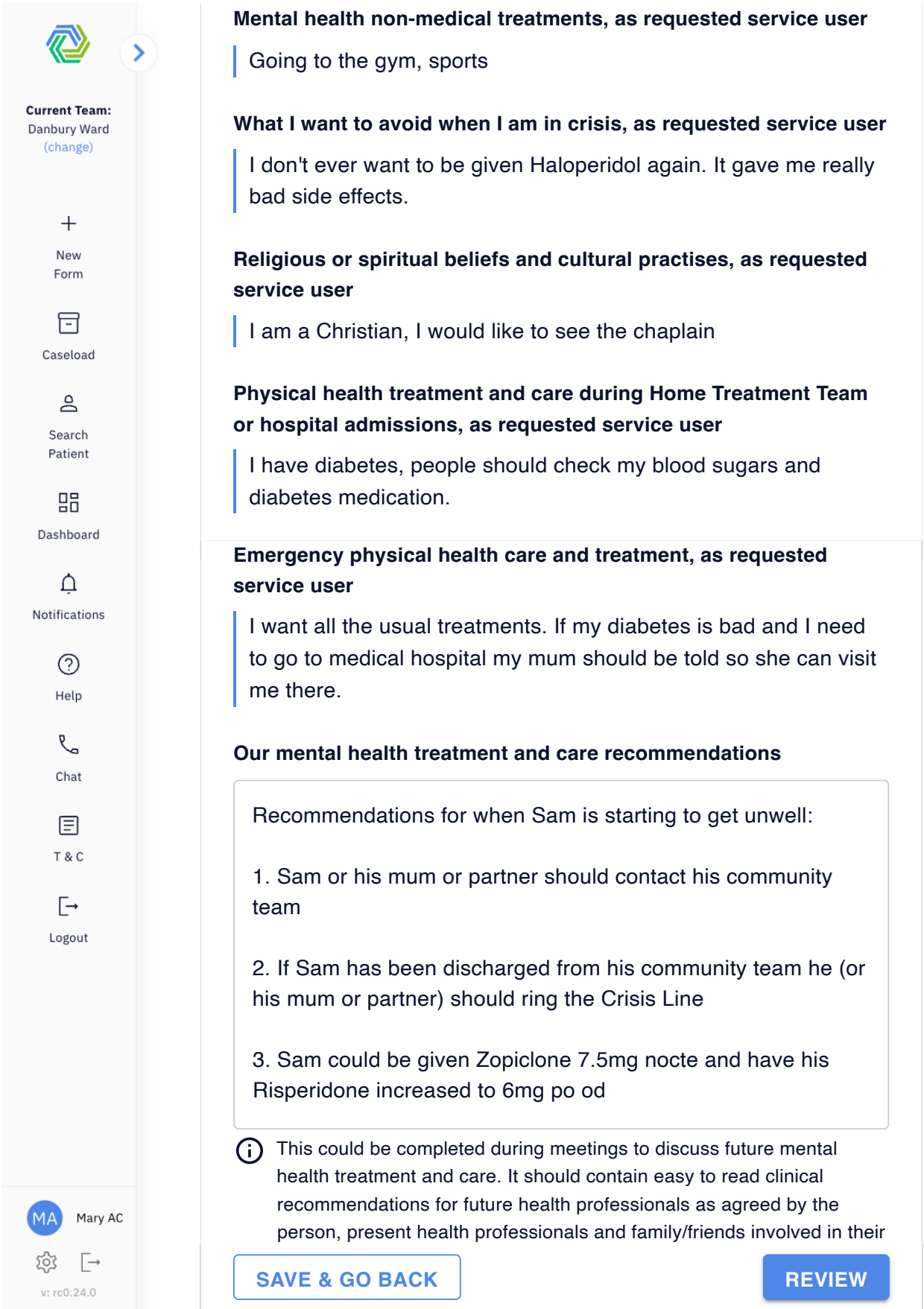
I want to make sure I stay safe. In the past I have got into embarrassing situations and spent all my money. I have said things I regret to my partner. I have posted embarrassing things on Instagram.

Continued on next page

Form ID: 2c4d05ca

Example 2A: Recommendations for treatment and care interface

The Facilitator can input recommendations for mental health treatment and care based on the Service user's preferences. Again, tooltips provide helpful prompts to the type of information that is useful to include.



Example 2B: Recommendations for treatment and care PDF

The Service user preferences and the Facilitator recommendations are displayed side by side to demonstrate equity in the importance of how this information should be considered by the reader.

NHS Number: unknown at time of completion

My preferences for treatment and care

Community/home treatment team crisis care

I have worked with home treatment team before and liked it. But I like to have familiar faces because I can find it difficult to trust people when I am unwell. If I am really unwell I might refuse to see home treatment team. I might not take medication or answer my phone

When I need admission to hospital

If I refuse to listen to anyone or start doing embarrassing things. My mum knows when I need to go to hospital. I usually say I don't want to go and will refuse to take any medication.

Mental Health Act Assessment (being sectioned)

My mum should be told, people should speak to me calmly and explain what is going on. I will get more angry if people don't tell me what is happening.

Hospital care

I am a smoker and want to be prescribed patches as soon as I get into hospital. I want to be able to ring my partner and my mum. I calm down if people talk calmly to me and tell me what is going on. I have an injury on my right leg. If people restrain me they shouldn't put pressure on my right knee. I want my mum to be invited to ward rounds.

Our mental health treatment and care recommendations

Recommendations for when Sam is starting to get unwell:
1. Sam or his mum or partner should contact his community team
2. If Sam has been discharged from his community team he (or his mum or partner) should ring the Crisis Line
3. Sam could be given Zopiclone 7.5mg nocte and have his Risperidone increased to 6mg po od

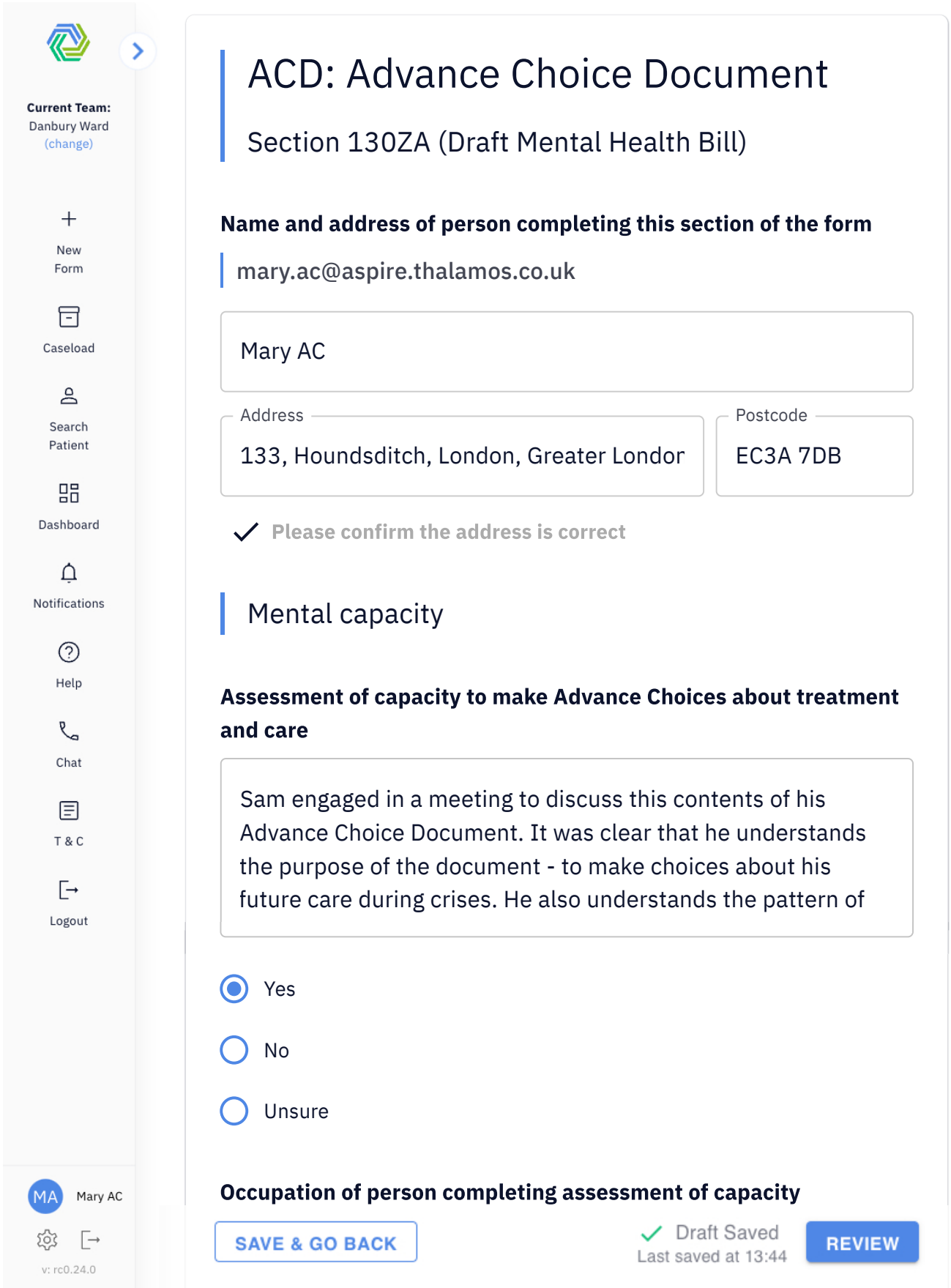
Recommendations for when Sam is very unwell:
1. Consult Sam's mum and partner about whether they feel he could work with HTT or whether MHA Ax and admission is required - specifically assess for any concerns about the safety of Sam's mum as Sam can behave very uncharacteristically when he is unwell.
2. Avoid Haloperidol as per Sam's wishes. He has experienced significant EPSE in the past.
3. Olanzapine may be effective as prn but should not bestarted as a long term medication due to weight gain and impact on diabetes management.
4. Sam is known to Dr Blue and the diabetes specialist nurses at Central Hospital. This team should be consulted if there are concerns about managing his blood sugars.

Continued on next page

Form ID: 2c4d05ca

Example 3A: Mental capacity interface

A Clinician can record the details of their capacity assessment and indicate whether the person has capacity to make advance choices about treatment and care. If the Clinician does not feel the person has capacity or they are unsure, they must document their conclusion.



Example 3B: Mental capacity PDF

Demonstration of how the information entered in Example 3A is displayed in the final PDF document.

NHS Number: unknown at time of completion

Mental Capacity

Assessment of capacity to make advance choices about treatment and care

Sam engaged in a meeting to discuss this contents of his Advance Choice Document. It was clear that he understands the purpose of the document - to make choices about his future care during crises. He also understands the pattern of what can happen during crises and the kind of treatment care he needs in terms of support, hospital admission and medication. He was able to use and weigh this information to make choices about future medication and communicate it verbally and in writing. I have no concerns about his capacity to make advance choices about his treatment and care at this point in time.

Does the person have capacity to make advance choices about treatment and care?

Yes / ~~No~~ / ~~Unsure~~

Name / Occupation of clinician

Mary AC (Clinician)

10/05/2023 *(Date of capacity assessment)*

Continued on next page Page 14 of 17

Form ID: 2c4d05ca

Example 4A: Service user signature interface

Each person involved in the creation of the ACD must sign the document to show that it has been completed collaboratively and the information is mutually agreed.

Example 4B: Signature page PDF

Demonstration of how the information entered in Example 4A is displayed in the final PDF document.

People involved in making this Advance Choice Document

This document contains information about the service user's advance choices for treatment and care during mental health crises. These choices have been made with the service user's treating team and supporters. Health professionals should access and carefully consider the contents of this Advance Choice Document (ACD) to inform decisions about the service user's treatment and care, particularly if this treatment and care is involuntary (i.e. given under the Mental Health Act). This ACD should be used when considering detention during Mental Health Act assessments and when creating care and treatment plans during an admission. There is no legal obligation to follow a choice expressed in an ACD if the professional reasonably believes that to do so would be to put the service user or others at risk of serious harm. However, the professional should be prepared to document the reason for not following a choice expressed in an ACD and explain this to the service user.

Name of Clinician

Mary AC

I confirm I have been involved in making this Advance Choice Document

Signed

Date

22/08/2023

Name of Service user

Sam Brown

I confirm I have been involved in making this Advance Choice Document

We would like to update this document in

1 year

Signed

Date

22/08/2023

Continued on next page

Form ID: 27d85c7b

Advance Choice Document

My details and personal information

Name

Sam Brown

Date of Birth

10/04/1986

NHS Number

1111111111

Ethnicity

Not known

Gender

Not stated (person asked but declined to provide a response)

Trust ID

11-11-11

Who I Am

What I'm like when I am well (please consider these things when I am in crisis)

I am friendly and calm, I enjoy seeing my friends and family. I am studying music and have a part time job in a coffee shop. I go to all my health appointments.

Continued on next page

Form ID: 27d85c7b

Health difficulties

Main mental health difficulties

I have bipolar, I get manic and depressive episodes

Main physical illness and/or allergies

I have diabetes

Learning difficulties, communication difficulties and/or other significant diagnoses

None

Continued on next page

Care in Crisis

Things that have led to me becoming unwell before

Getting stressed at work, not sleeping well, when I had a relationship break up.

Key signs that I am in crisis

I stay up very late and start posting more on instagram. I stop taking care of myself and can overspend and get into debt. I can start to feel that people are against me and might be trying to hurt me. I will refuse to go to my health appointments and might stop taking my medication.

Early signs that I am losing capacity to make decisions

My partner and my mum know when I am not myself. I start speaking very fast. I can think that the doctors are trying to poison me and I feel unsafe. I can hear voices telling me things I don't want to do. I might not talk to you, I might pace around or shout at you. I might refuse to take any medication or to see health professionals.

Key things I want to avoid

I want to make sure I stay safe. In the past I have got into embarrassing situations and spent all my money. I have said things I regret to my partner. I have posted embarrassing things on Instagram.

Continued on next page

Key things people misunderstand about me when I'm unwell

Sometimes people don't always realise how unwell I am. I can hold it together and speak convincingly when there are health professionals there.

Continued on next page

My preferences for treatment and care

Community/home treatment team crisis care

I have worked with home treatment team before and liked it. But I like to have familiar faces because I can find it difficult to trust people when I am unwell. If I am really unwell I might refuse to see home treatment team. I might not take medication or answer my phone

When I need admission to hospital

If I refuse to listen to anyone or start doing embarrassing things. My mum knows when I need to go to hospital. I usually say I don't want to go and will refuse to take any medication.

Mental Health Act Assessment (being sectioned)

My mum should be told, people should speak to me calmly and explain what is going on. I will get more angry if people don't tell me what is happening.

Hospital care

I am a smoker and want to be prescribed patches as soon as I get into hospital. I want to be able to ring my partner and my mum. I calm down if people talk calmly to me and tell me what is going on. I have an injury on my right leg. If people restrain me they shouldn't put pressure on my right knee. I want my mum to be invited to ward rounds.

Our mental health treatment and care recommendations

Recommendations for when Sam is starting to get unwell:

1. Sam or his mum or partner should contact his community team
2. If Sam has been discharged from his community team he (or his mum or partner) should ring the Crisis Line
3. Sam could be given Zopiclone 7.5mg nocte and have his Risperidone increased to 6mg po od

Recommendations for when Sam is very unwell:

1. Consult Sam's mum and partner about whether they feel he could work with HTT or whether MHA Ax and admission is required - specifically assess for any concerns about the safety of Sam's mum as Sam can behave very uncharacteristically when he is unwell.
2. Avoid Haloperidol as per Sam's wishes. He has experienced significant EPSE in the past.
3. Olanzapine may be effective as prn but should not bestarted as a long term medication due to weight gain and impact on diabetes management.
4. Sam is known to Dr Blue and the diabetes specialist nurses at Central Hospital. This team should be consulted if there are concerns about managing his blood sugars.

Continued on next page

Mental health medical treatments

I take Risperidone and this works ok for me. It is ok if the dose is increased when I am in hospital. Getting sleep helps me I might need tablets for this. If I really need it I don't mind having Olanzapine as a one off but I don't want it long term as its very bad for my diabetes.

Mental health non-medical treatments

Going to the gym, sports

Treatment and care I want to avoid

I don't ever want to be given Haloperidol again. It gave me really bad side effects.

Religious or spiritual beliefs and cultural practises

I am a Christian, I would like to see the chaplain

Physical health treatment and care during Home Treatment Team or hospital admissions

I have diabetes, people should check my blood sugars and diabetes medication.

Emergency physical health care and treatment

I want all the usual treatments. If my diabetes is bad and I need to go to medical hospital my mum should be told so she can visit me there.

Continued on next page

Practical help

Home

Check my home is secure: ~~Yes~~ / No

Throw away any perishable foods or drinks: ~~Yes~~ / No

Care arrangements

Do you need to arrange care for children: Yes / ~~No~~

My partner has a daughter who I pick up from school and can take home on Fridays. If I am unwell on this day the school and my partner should be informed.

Do you need to arrange care for dependent relative(s): Yes / ~~No~~

I help my mum out with her shopping and jobs round the house. It would be good if someone could ask her if she needs help if I am in hospital - she might not ask for help herself.

Do you need to arrange care for pet(s): Yes / ~~No~~

I have a dog, my partner has agreed to take care of him if I am in hospital.

Do you need to arrange any other care?: Yes / ~~No~~

I have a brother who has a disability and is in residential care. I visit him. I would like someone to tell him why I am not visiting him as usual.

Is there anyone you want to be informed if you are admitted: Yes / ~~No~~

Name: Stephanie Pink

Relationship: My boss at the coffee shop

Phone number: 01111111111

What would you like to inform them: Let her know I need to take some sick leave.

Continued on next page

Is there anyone else you want to be informed if you are admitted: ~~Yes~~ / No

Is there anyone you don't want to be informed if you are admitted: ~~Yes~~ / No

Continued on next page

Key Crisis Supporters

Preferred Contacts

Name: Pat Brown

Relationship: Mother

Role in crisis: My mum provides a lot of emotional and practical support.

Phone number: 01111111111

Address: Test address, TEST

This is my nearest relative to be contacted when a Mental Health Act (MHA) assessment is being conducted

Is this person your nearest relative according to the Mental Health Act 1983?

Yes / ~~No~~ / ~~Unsure~~

Is there any reason why you would prefer your nearest relative is not contacted? ~~Yes~~ / No

Do you have a second preferred contact: ~~Yes~~ / No

Other crisis supporters

Do you have a Care Co-ordinator contact? Yes / ~~No~~

Name: Test

Organisation: Test

Phone number: 01111111111

Do you have a Consultant contact? Yes / ~~No~~

Name: Test

Organisation: Test

Phone number: 01111111111

Continued on next page

Do you have a GP contact? Yes / ~~No~~

Name: Test

Organisation: Test

Phone number: 01111111111

Do you have any other key crisis supporter contacts? ~~Yes~~ / No

Continued on next page

How people can access this Advance Choice Document

How can the ambulance service access this document?

My mum could give the ambulance service a copy of this document.

How can A&E staff access this document?

A&E staff could access this document by being given a paper copy or contacting the psychiatric liaison team to look through my electronic mental health records.

How can general hospital staff access this document?

General hospital staff could ask the psychiatric liaison team to look at my electronic mental health records.

Continued on next page

How can mental health trust staff access this document?

This document will be uploaded on my electronic mental health records.

How can Approved Mental Health Professionals (AMHPs) access this document?

They can contact my mental health team or the psychiatric liaison team to access a copy.

How can GPs access this document?

My GP will be asked to upload a copy on their electronic system.

Can family and/or friends access this document: Yes / ~~No~~

Use first preferred contact: Yes / ~~No~~

Continued on next page

Name: Pat Brown

How they can access this document: My mum has a paper copy of this document at home.

Add another person: ~~Yes~~ / No

Can anyone else access this document: ~~Yes~~ / No

Continued on next page

Mental Capacity

Assessment of capacity to make advance choices about treatment and care

Sam engaged in a meeting to discuss this contents of his Advance Choice Document. It was clear that he understands the purpose of the document - to make choices about his future care during crises. He also understands the pattern of what can happen during crises and the kind of treatment care he needs in terms of support, hospital admission and medication. He was able to use and weigh this information to make choices about future medication and communicate it verbally and in writing. I have no concerns about his capacity to make advance choices about his treatment and care at this point in time.

Does the person have capacity to make advance choices about treatment and care?

Yes / ~~No~~ / ~~Unsure~~

Name / Occupation of clinician

Mary AC (Clinician)

10/05/2023 *(Date of capacity assessment)*

Continued on next page

Other views

Summary of other consultations

Consultation with diabetes team:
Sam's case has been discussed with his diabetes team. He is under the care of Dr Blue at Central Hospital. They are happy to be contacted to provide liaison care and phone advice if Sam is admitted to mental health hospital.

Additional comments that have not already been covered

Not answered

Continued on next page

People involved in making this Advance Choice Document

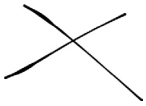
This document contains information about the service user's advance choices for treatment and care during mental health crises. These choices have been made with the service user's treating team and supporters. Health professionals should access and carefully consider the contents of this Advance Choice Document (ACD) to inform decisions about the service user's treatment and care, particularly if this treatment and care is involuntary (i.e. given under the Mental Health Act). This ACD should be used when considering detention during Mental Health Act assessments and when creating care and treatment plans during an admission. There is no legal obligation to follow a choice expressed in an ACD if the professional reasonably believes that to do so would be to put the service user or others at risk of serious harm. However, the professional should be prepared to document the reason for not following a choice expressed in an ACD and explain this to the service user.

Name of Clinician

Mary AC

I confirm I have been involved in making this Advance Choice Document

Signed



Date

22/08/2023

Name of Service user

Sam Brown

I confirm I have been involved in making this Advance Choice Document

We would like to update this document in

1 year

Signed

Date

22/08/2023

Continued on next page

Form ID: 27d85c7b

Name of Facilitator

Mackenzie ACD Facilitator

I confirm I have been involved in making this Advance Choice Document

Signed

Date

22/08/2023

Form ID: 27d85c7b